

Memory-Making in Neonatal End-of-Life Care

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Abstract

Experiencing the death of an infant places parents at risk of prolonged and profound grief, therefore providing appropriate psychosocial support for parents is crucial. Current perinatal palliative care guidelines recommend memory-making activities, such as collecting or creating mementos and spending time caring for the infant, as an important aspect of bereavement care. However, evidence to support such interventions is scant. This study used the grounded theory method described by Corbin and Strauss (2015) to explore bereaved parents' experiences of memory-making in neonatal end-of-life care. Eighteen bereaved parents participated in extensive semi-structured interviews. The core psychosocial process underpinning parents' experience of memory-making was identified as "Affirmed Parenthood". This core category was supported by three key themes; "Being a parent", "Creating evidence" and "Being guided". "Being a parent" included spending time with the baby before and after death, touching and holding the baby, and providing physical care. "Creating evidence" captured parents' efforts to collect or create tangible evidence of their baby's life through photographs and other mementos, and by involving others with their baby to ensure that people outside the immediate family would have memories of their child. Finally, "Being guided" represented parents' need to be supported and encouraged throughout the process of memory-making. Where all three key themes were addressed in bereavement care, parents experienced affirmation of the significance of their baby's life, affirmation of the significance of their loss, and affirmation of their role as the baby's parents.

Declaration

This declaration is to certify that this thesis comprises only my original work towards the qualification of Doctor of Philosophy. Due acknowledgement has been made in the text to all other material used. This thesis is 74,324 words in length, excluding tables, appendices and reference list.

Student Name Rebecca Kate Thornton

Signature

Date 28th February 2019

Abbreviations

ABS	Australian Bureau of Statistics
ACNN	Australian College of Neonatal Nurses
BAPM	British Association for Perinatal Medicine
CDC	Centers for Disease Control
DHS	Department of Human Services (Victoria)
NANN	National Association of Neonatal Nurses (US)
NICE	National Institute for Health Care Excellence (UK)
NICU	Neonatal Intensive Care Unit
PSANZ	Perinatal Society of Australia and New Zealand
SCBU	Special Care Baby Unit
WHO	World Health Organization

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(I promise I won't do any more study.... for a bit).

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Chapter 1: **Introduction**

1.1 INTRODUCTION

An average of 2,520 families experience perinatal loss in Australia every year (Australian Bureau of Statistics [ABS], 2018). Whether before or after delivery, the death of an infant has been identified as placing parents at risk of complicated and often prolonged grief (Cacciatore, 2013; Kersting & Wagner, 2012). The loss of an infant entails not only the loss of a loved one but also the loss of an imagined future and the disruption of one's identity as a parent (Malacrida, 1997). Providing appropriate psychosocial care is therefore vital in promoting optimal outcomes for bereaved parents experiencing the loss of an infant (Edi-Osagie & Evans, 2005; Gold, 2007; McGuinness, Coughlan, & Power, 2013).

Currently, practices are recommended in Australian and international perinatal and neonatal palliative care guidelines, with the intention of helping parents to create memories with their baby. Such practices include seeing and holding the baby, participating in rituals, and collecting or creating mementos. However, these practices are primarily based on anecdotal evidence, or studies with parents experiencing loss in different contexts, such as stillbirth or miscarriage. Little is currently known about the significance parents attach to memory-making activities, or the impact of these activities on parents' experience of neonatal bereavement. This grounded theory study redresses

this gap, making an original contribution to the knowledge guiding memory-making practices in neonatal end-of-life care.

This chapter describes the impetus for this grounded theory study and situates it within current clinical practice recommendations. A brief overview of current research around memory-making in perinatal and neonatal end-of-life care is provided, while opportunities for further research are explored. The research questions addressed in this study are described, and an overview of the thesis is provided.

1.2 IMPETUS FOR THE STUDY

Over the past fifteen years, I have had the honour of providing end-of-life care for a number of children and their families. Having the opportunity to provide some small comfort during such an intensely difficult time for families has been an incredible privilege; at times both emotionally taxing and profoundly rewarding. In 2013, I was working in a clinical role in a major metropolitan Neonatal Intensive Care Unit (NICU). In this context, I observed that end-of-life care for babies often included interventions such as the collection or creation of mementos of the baby. While I had occasionally engaged in these practices while caring for older children, it appeared as though they were a common and almost ritualised element of care in the neonatal unit. I reviewed the clinical practice guidelines and found that such practices were indeed recommended. However, I noticed that these sections of the guidelines were frequently unreferenced, or were reliant on a handful of references, lacking the footnotes so prolific in sections regarding symptom management or clinical decision making. A brief review of the literature confirmed that there was very little evidence regarding memory-making as a

bereavement intervention in the neonatal context. This discovery concerned me for several reasons. I wondered whether there was a potential to cause unintentional harm through the use of unevaluated interventions. I also wondered whether the interventions that were being recommended constituted best practice from the perspective of the bereaved families. While some evaluation of perinatal bereavement programs had been conducted, there was limited research exploring parents' perceptions of memory-making practices in the neonatal setting. Finally, I wondered how parents perceived these interventions as affecting their bereavement experience. Of the few studies that explored memory-making interventions, fewer still explored the outcomes of such practices from the perspective of the parent. These concerns eventually evolved into the research questions that underpin this study. My intention in undertaking this study was to provide a localised theory to inform memory-making practices in neonatal end-of-life care, with a view to promoting optimal outcomes for bereaved parents.

1.3 BACKGROUND

1.3.1 Defining the setting

In the following chapters, the term 'neonatal unit' will be used to describe an acute care setting which provides care to infants from birth up to (or beyond) 28 days post-term. In the Australian context, neonatal units include both Neonatal Intensive Care Units (NICUs), which are acute care units with the capacity to provide life sustaining treatment, and Special Care Units, which provide acute and supportive care. Neonatal units typically admit infants from birth to 28 days of age, although infants who are pre-term, or who have complex or life-limiting conditions may receive care in the neonatal

unit for weeks or months. The broader term neonatal unit is used to capture parents whose infants received end-of-life care in either a NICU or Special Care Unit.

1.3.2 Terminology in infant loss

Within the literature, numerous terms are used to describe deaths occurring before, during and soon after birth, and these terms may at times be used interchangeably. For example, 'stillbirth' typically refers to the birth of an infant near or at term without signs of life. However, there is no universally accepted threshold that divides stillbirth from miscarriage. The World Health Organization [WHO] recommends defining stillbirths as intrauterine deaths occurring at 28 weeks of completed gestation (WHO, 2016), while other research institutions from developed countries define stillbirths as intrauterine deaths occurring from 20 weeks (ABS, 2018; Centers for Disease Control, 2018) or 24 weeks of completed gestation onward (Royal College of Obstetricians and Gynaecologists, 2010). In Australia, stillbirth is defined as occurring when an infant is born without signs of life at 20 weeks gestation, or with a birth weight in excess of 400 grams (Perinatal Society of Australia and New Zealand [PASANZ], 2018). As opposed to stillbirth, which occurs in-utero, 'neonatal death' is defined as the death of an infant, who is born with signs of life, occurring any time between delivery and 28 days post-partum (WHO, 2016).

Throughout the literature, the term 'perinatal death' is frequently used to address both stillbirths and neonatal deaths. However, as with stillbirth, there is a lack of consistency in defining the perinatal period. For instance, perinatal loss has been defined by the World Health Organization as commencing at "at 22 completed weeks (154 days) of gestation" and ending "seven completed days after birth" (WHO, 2006, p.6). This

definition is narrower than that used by many researchers, who combine the broader definition of stillbirth described above (occurring from 20 weeks completed gestation) with the broader definition of neonatal death (occurring up to 28 days post birth) (Barfield, 2011). Inconsistency in language and a lack of agreed definitions make finding and interpreting literature relevant to the clinical context challenging.

1.3.3 Defining perinatal bereavement.

Given the lack of consistency in terminology and lack of conceptual clarity around definitions of the perinatal period, it is perhaps more pertinent to frame the research utilised in this thesis by providing a working definition of perinatal bereavement based on current evidence. Fenstermacher and Hupcey (2013) undertook a principle-based analysis of the concept of perinatal bereavement. Their detailed conceptual definition states that perinatal bereavement, secondary to the death of an infant before, during or after birth can be described as:

A complex emotional response, most commonly manifested as grief in both the mother and father, but often expressed differently between males and females, both in intensity and duration. The grief response of perinatal bereavement is influenced by situational, internal and external factors. (Fenstermacher & Hupcey, 2013, p.2394)

The authors go on to explain that factors such as culture and faith impact on the mourning which occurs in relation to perinatal loss. Perhaps most interestingly, one of the elements of this conceptual definition explicitly identifies the role of memory-making in perinatal bereavement:

There is no prescribed timeframe for perinatal bereavement, although bereavement support interventions such as creating mementos, naming the baby, holding the baby and having a funeral service may decrease the intensity and duration of the grief response during perinatal bereavement.

(Fenstermacher & Hupcey, 2013, p.2394)

This definition shifts the focus from arbitrary gestational ages and instead considers the parents' experience of bereavement as the key defining feature of perinatal loss. It is particularly instructive that this concept analysis specifically revealed memory-making as a central component of the theoretical definition of perinatal loss, given the focus of the current study.

1.3.4 The significance of perinatal loss.

The grief experienced by parents has been identified as both particularly profound and especially enduring (Arnold & Gemma, 2008; Klass, 1993). For example, the authors of one study reported that bereaved parents had significantly higher scores on a validated grief inventory than a normative population of young people who had experienced the death of a close relative (Michon, Balkou, Hivon, & Cyr, 2003). Infant and child loss is also potentially associated with an increased incidence of 'complicated grief' (Kersting & Wagner, 2012; Zetumer et al., 2015).

While complicated grief is a contentious concept, it has been defined in the literature as grief that is "more disruptive, pervasive and long lasting than a normal grief response" (Kersting & Wagner, 2012, p. 188). A study of perinatally bereaved mothers in Australia found that 12.4% of mothers attending a bereaved parent group were assessed as having "complicated grief scores in the clinical range", a significantly higher number

than those in a normative population of bereaved adults (McSpedden, Mullan, Sharpe, Breen & Lobb, 2017, p. 112). These elevated grief scores imply that these parents were experiencing profound distress which impacted significantly on function over time. Indeed, the authors reported that these elevated scores persisted, with many of these participants continuing to experience complicated grief which impact their daily lives five years post loss.

Many authors have described the potential for prolonged grieving in the context of child or infant loss (Kersting, Braehler, Glasmer & Wagner, 2011; Klass, 1993; Koopmans, Wilson, Cacciatore & Flenady, 2013). For example, in an essay stemming from a longitudinal ethnographic study of bereaved parents, Klass (1993) described parental bereavement as “a permanent condition”, explaining that the parents in his study experienced their loss as a death of part of themselves. He argued that bereaved parents may learn to invest in other relationships and “grow in those parts of themselves which did not die with the child”, but that “a part of them is missing and their world is forever diminished” (p. 344).

In addition to prolonged or complicated grief, trauma-related symptoms may also be enduring in parents experiencing perinatal loss. A multivariate regression analysis comparing perinatally bereaved parents with a normative sample of parents found that a range of adverse psychological outcomes, including elevated trauma symptoms, were apparent in parents up to five years after perinatal loss (Murphy, Shevlin & Elklit, 2014). While the majority of studies have focused on grief responses, a range of other psychological outcomes, including Post-Traumatic Stress disorders may also be associated with perinatal loss.

While any form of loss can result in grief and trauma, the loss of an infant before, or soon after birth may present a number of unique challenges. Malacrida (1997), herself a bereaved parent, captures the complex nature of perinatal bereavement, explaining that perinatal grief “touches on our beliefs about gender, parenthood, responsibility, worthiness, the innocence and promise of childhood, the world as predictable, and our beliefs of ourselves as capable, resilient individuals” (p.131). The capacity for perinatal loss to threaten the identity of the parent has been consistently described in the literature (Crawley, Lomax & Ayers, 2013; Lathrop & VandeVusse, 2011; Lovell, 1983; Malacrida, 1997; Robinson, Baker, & Nackerud, 1999). Becoming a parent is a significant developmental milestone, while the loss of a baby may leave parents feeling that they have not only lost a child, but that they have also lost a part of themselves (Bennett, Litz, Maguen, & Ehrenreich, 2008; Keesee, Currier, & Neimeyer, 2008). This relationship between parental identity and perinatal loss will be explored in more depth in Chapter Three.

Parents experiencing the loss of an infant not only contend with threats to their sense of self, but they may also experience the loss of hopes and dreams invested in their child (Fenstermacher & Hupcey, 2013; Malacrida, 1997; Rando, 1986). As described by Callister (2006), perinatal loss includes the loss of a loved and anticipated child, but also “the loss of dreams and hopes; and the loss of an extension of both parents...When one loses a parent through death, the past is lost. In contrast, when a child dies, one has lost the future” (p.228). In this sense, perinatal loss represents multiple losses for parents; loss of an anticipated future, loss of hopes and loss of part of ones’ self.

In developed countries, the death of a child is also considered a rare and untimely event. As described by Keesee, Currier and Neimeyer (2008), the loss of a child is “inherently out of synchrony with the family life cycle and violates the perceived order of natural living” (p.1146). This view of child death as unnatural or untimely may make it more difficult for parents to come to terms with their loss.

More profoundly, the unexpected nature of child death may threaten the “assumptive world” of the parent. The concept of the assumptive world is used to describe the often-unconscious assumptions that we hold about the world and the ways that traumatic experiences, such as bereavement, can challenge or even destroy these assumptions (Janoff-Bulman, 1989; Parkes, 1975). Beder (2005) explains that the assumptive world constitutes the:

Assumptions or beliefs that ground, secure, stabilise, and orient people. They are our core beliefs. In the face of death and trauma, these beliefs are shattered and disorientation and even panic can enter the lives of those affected. In essence, the security of their beliefs has been aborted. (p.255).

As described by Maple, Edwards, Minichiello and Plummer (2013) “the death of a child can shatter assumptions that the world is a fair and just place, that it is predictable and controllable” (p.57). In this sense, the loss of an infant is more than the loss of an embodied loved one. Perinatal loss may disrupt the way that parents view themselves, how they experience their social roles, and even how they view the world. Providing psychosocial care that acknowledges the multiple losses that are entailed in perinatal or neonatal death is vital in promoting the best possible outcomes for bereaved parents.

1.4 GAPS IN THE LITERATURE

While the significance of perinatal bereavement is increasingly being acknowledged in the literature, comparatively few studies have explored bereavement interventions utilised with perinatally or neonatally bereaved parents in detail. As highlighted in a 2013 Cochrane Review, a lack of quality evidence means that "the true benefits of currently existing interventions aimed at providing support for mothers, fathers and families experiencing perinatal death is unclear" (Koopmans et al., 2013, p.2). In particular, there is a significant gap in the literature concerning bereavement support for parents experiencing the loss of a baby in the neonatal period. The majority of current research is focused exclusively on parents experiencing stillbirth or explores parents' needs around perinatal loss more broadly.

Although some of the studies exploring perinatal loss include data from parents whose babies died in the neonatal period, applying evidence from these studies to guide practice in neonatal units is potentially problematic. There may be more opportunities for memory-making in situations where babies are live-born and spend hours or days in the neonatal unit before death, while some memory-making activities may hold different meanings for parents of live-born infants compared with parents who have experienced a stillbirth.

For example, interventions that encourage contact between parents and their stillborn baby remain somewhat contentious (Cacciatore, Rådestad, & Frederik Frøen, 2008; Hughes, Turton, Hopper, & Evans, 2002), however, this is less true in the context of babies who survive delivery and receive care in a neonatal unit. Indeed, neonatal

palliative care guidelines repeatedly refer to the need to encourage contact between parent and child (Lisle-Porter & Podruchny, 2009; Reid et al., 2011). A systematic review of bereavement interventions in NICUs found that parents consistently valued the opportunity to hold their baby while the baby was still alive (Harvey, Snowdon, & Elbourne, 2008). In this sense data from studies that combine stillbirths and neonatal deaths under the broader category of perinatal loss may not accurately reflect the specific needs and experiences of parents whose babies receive end-of-life care in the neonatal unit.

Research specific to end of life care in the context of the neonatal unit is particularly important given that the majority of deaths in the first months of life occur in neonatal units. A study of neonatal mortality across New South Wales and the Australian Capital Territory found that the majority of deaths in the newborn period occurred in a neonatal unit, while less than five percent of death occurred at home; a figure that has remained relatively unchanged between 1995 and 2006 (Feng, Abdel-Latif, Bajuk, Lui & Oei, 2013). Similarly, data from the Australian Institute of Health and Welfare (2016) indicate that between 1993 and 2012, less than four percent of neonatal deaths in Victoria, Queensland, Tasmania and South Australia occurred outside the acute hospital setting. Given the proportion of neonatal deaths that occur in neonatal units, it is vital that health professionals working in these environments are equipped with the knowledge and skills to provide the best possible end-of-life care for newborns and their families.

1.5 PURPOSE OF THE STUDY

The purpose of this study was to develop a substantive theory of memory-making in neonatal end-of-life care, using the grounded theory approach proposed by Corbin and Strauss (2008; 2015). Substantive theories are designed to aid “understanding of a tangible phenomenon in a clearly defined situation” (Birks & Mills, 2011, p.156) and do not necessarily need to be transferrable between settings. Such theories are distinct from “formal” theories that are more abstract in nature and therefore have applicability across multiple substantive areas (Birks & Mills, 2011). In addition to the development of a substantive theory, data from this study may also be used to inform education programs for health professionals caring for critically ill newborns and their families in NICU and special care nursery settings.

1.5.1 Research questions.

The place of the research question in grounded theory research is contested. Glaser (1992) claims that one should enter the field without specific questions, but rather with a sense of “abstract wonderment” about what is occurring, or about how a problem is handled (Glaser, 1992, p. 22). Conversely, Corbin and Strauss (2015) argue that “broad and open-ended” research questions can provide an essential focus for the study, without constraining the development of the grounded theory (p.54). In keeping with Corbin and Strauss’s approach, two broad and open-ended questions were developed to guide the current enquiry:

1. *What significance do memory-making activities hold for parents experiencing the loss of an infant in the neonatal unit? And,*
2. *What is the impact of memory-making activities on parents experiencing the loss of an infant in the neonatal unit?*

1.6 OVERVIEW OF THE THESIS

Chapter One of this thesis provides relevant background information, including a brief overview of the potential impact of perinatal loss on bereaved parents. Direction is also provided for the research regarding a clear purpose and research questions. Finally, an outline of the remainder of the thesis is presented.

In grounded theory research, the timing of the literature review is contentious. In their earliest work, Glaser and Strauss (1967) argue that the researcher should at first “literally ignore the literature” (p.37). In contrast, Corbin and Strauss (2015) take a more moderate view, acknowledging that some familiarity with the literature is essentially unavoidable, and that literature can be used to enhance the researcher’s theoretical sensitivity. However, they too caution that researchers should “avoid becoming so steeped in the literature that they are constrained and even stifled by it” (Corbin & Strauss, 2015, p.49). For this reason, the in-depth reviews of the literature presented in Chapters Two and Three were conducted *after* data collection and analysis were completed, to ensure that analysis was not unduly influenced by preconceived ideas.

Two critical reviews of the literature were conducted to provide context for the current study, and to identify gaps in the existing literature. Firstly, the existing evidence surrounding memory-making as an intervention with bereaved parents was reviewed and is presented in Chapter Two. Subsequently, the literature surrounding grief and loss was examined to identify theoretical structures that may provide insight into the impact and significance of memory-making interventions for perinatally bereaved parents. The findings of this second literature review are presented in Chapter Three.

Chapter Four describes the methodology that underpinned this study, and in particular, describes the rationale for choosing a Straussian approach to grounded theory rather than a classic or Glaserian approach. Chapter Four also explicates the research process used in the current study, from ethical considerations, recruiting and sampling, through to data collection and analysis. The findings of this research are presented in Chapters Five, Six and Seven. Each findings chapter explores one of the major categories developed from the data, using verbatim quotes from participants to illuminate key concepts.

Chapter Eight situates the findings of the current study within existing research around memory-making in perinatal end-of-life care, describing both the congruence between the findings of the current study and the broader perinatal palliative care literature, and the findings that were unique to this study. Lastly, Chapter Nine provides an outline of the substantive theory 'Affirmed Parenthood', explaining how the concepts and categories described in the findings fit together to form a cogent model of memory-making in the neonatal end-of-life context. A discussion around the strengths and limitations of the research is presented, and consideration is given to the clinical

implications of this research and the potential barriers to practice change. Finally, potential directions for future research in the care of bereaved parents are described.

Chapter 2: **Memory-Making in Perinatal End-of-Life**

Care: A Critical Review

2.1 INTRODUCTION

The aim of this study was to understand the impact and significance of memory-making interventions for parents experiencing the death of a newborn in the acute neonatal care setting. This literature review critically examines original studies, systematic reviews, and guidelines relating to memory-making interventions for bereaved parents, providing an overview of current research, and identifying potential gaps in the literature. This literature review is presented at the beginning of the thesis to provide the context for the current study. However, as noted in the previous chapter, the review was conducted *after* data collection and data analysis to ensure that the analysis was not constrained or coloured by existing research. This helped to ensure that the emerging theory was genuinely grounded in parents' experiences of memory-making in neonatal end-of-life care.

2.2 BACKGROUND

2.2.1 Defining Memory-Making.

Perinatal and neonatal palliative care guidelines increasingly include interventions designed to encourage parents to create memories with their baby. These interventions include supporting families to see, hold and spend time with their baby before and after death (Australian College of Neonatal Nurses [ACNN], 2010; British Association for Perinatal Medicine [BAPM], 2010; National Association of Neonatal Nurses [NANN], 2015; National Institute for Health Care Excellence [NICE], 2016; Perinatal Society of Australia and New Zealand [PSANZ], 2018; Victorian Department of Health and Human Services [DHS], 2017). Parents may also be encouraged to engage in caring activities such as bathing, changing nappies, or dressing the baby (ACNN 2010; BAPM, 2010; DHS, 2017; NANN, 2015; PSANZ 2018). The guidelines also recommend encouraging parents to name their baby and supporting parents to engage in personally meaningful rituals, such as baptisms, naming ceremonies, or blessings (ACNN 2010; BAPM, 2010; DHS, 2017; NANN, 2015; NICE, 2016; PSANZ 2018). Finally, the guidelines frequently suggest that staff help families to create mementos, such as photographs and hand or foot prints, and to collect items that might be of significance for the parents, such as the baby's clothing, blankets, and name bands (ACNN 2010; BAPM, 2010; DHS, 2017; NANN, 2015; NICE, 2016; PSANZ 2018). In this sense, memory-making activities can include any interactions that help parents form memories with their baby, as well as the collection or creation of mementos that serve as reminders of the baby. Despite this increasing

emphasis on memory-making practices within neonatal palliative care guidelines, few studies have specifically explored memory-making as a bereavement intervention for parents experiencing the loss of a newborn.

2.2.2 An overview of current clinical practice.

While the majority of perinatal palliative care guidelines incorporate recommendations regarding memory-making, it is important to consider how these guidelines are enacted in the clinical context. Several studies have examined end-of-life and bereavement care practices in a variety of paediatric and perinatal settings. For example, a postal survey of 200 neonatal units in the UK found that ninety nine percent of units provided photographs of the infant, while ninety-seven percent provided footprints or handprints (Robertson, Aldridge & Curley, 2011). Almost all of the units who responded to the survey also supported parents to be present with their baby at the time of death. Interestingly, among the same units, availability of memory boxes varied from fifty-eight percent in low acuity units to sixty-eight percent in high-acuity units (Robertson et al., 2011). A similar study was undertaken in neonatal units across Sweden. The authors report that “The majority of units, 97%, collected mementoes from the dead neonate, and asked the parents to nurse and dress the neonate after death” (Lundqvist, Nilstun & Dykes, 2003, p.201). In addition, they found that “91% of units encouraged the parents to perform technical care themselves such as tube feeding and 100% of units offered name giving” (p.200). This data indicates that while specific practices vary between units, most parents are provided

with some tangible items designed to act as mementos and are encouraged to see and hold their baby before, during or after the baby's death.

As no studies were located that specifically examined memory-making interventions in Australia, it is acknowledged that practices in this country may be somewhat different. However, the author's own clinical experience suggests that a similar pattern exists in Australian neonatal units; most parents are encouraged to spend time with their baby and are provided with several mementos. Nevertheless, there remain significant variations in practice between units and between clinicians.

2.3 TYPES OF MEMORY-MAKING INTERVENTIONS

2.3.1 Contact with the baby.

Contact, through seeing, touching and holding the baby has been identified as a crucial aspect of bereavement care for parents experiencing the loss of a child (Abraham & Hendriks, 2017; Baughcum et al., 2017; Calhoun, 1994; Lasker & Toedter, 1994; Lemmer, Boyd & Forrest, 1991; Pector, 2004; Sadeghi, Hasanpour & Heidarzadeh, 2016). For example, Gold, Dalton & Schwenk (2007) conducted a systematic review of 60 studies exploring hospital-based care for parents experiencing perinatal loss. They report that:

Qualitative studies uniformly noted that nearly all parents who saw their infants found this experience valuable. In fact, parents frequently stated that they would have liked even more time or more opportunities to be with their child or that they had not had the opportunity to see the infant at all. (p.1159)

Indeed, a mixed-methods study conducted in the US by Lasker and Toedter (1994) found that 96.3% of parents felt that seeing the baby while they were alive was “essential”.

Similarly, another US-based study involving 55 perinatally bereaved mothers explored the degree to which common bereavement practices were helpful or unhelpful (Bennett et al., 2008). The majority (83%) stated that seeing the baby was extremely helpful, while 85% stated that holding the baby was extremely helpful. The authors report that contact with the infant, while they were still alive, enabled parents to form bonds and to create memories that helped them cope with their loss after their baby’s death. Contact with the baby was not associated with adverse outcomes in this study.

For many parents, holding the baby at the time of death may also be a meaningful but emotionally difficult experience (Kavanaugh & Hershberger, 2005; Lemmer, Boyd & Forrest, 1991; Pector, 2004). For example, in a Swedish phenomenological study involving 16 bereaved mothers, the authors found that mothers who had experienced the loss of a newborn were ambivalent about being with their baby as they died (Lundqvist et al., 2003). Participants in this study generally appreciated the opportunity to be present at the time of death, and to hold their baby

as they were dying, but also reported needing emotional support from staff during this time. Interestingly, several mothers who chose not to hold their baby during withdrawal of life support reported that they felt pressured to do so, and perceived this pressure as indicating a lack of empathy from healthcare providers. This response left mothers feeling that they had been judged for their decision not to hold their dying baby. Findings such as this highlight the need to encourage parents to have contact with their baby, but to appreciate that some parents may not feel comfortable or capable of holding their baby as they die.

Finally, contact with the baby after death may also be a significant aspect of care for parents. For example, Abraham and Hendriks (2017) conducted a retrospective qualitative study in Switzerland involving 20 parents who had experienced neonatal loss. They report that “all parents felt the need to spend some time with their deceased baby even though this varied from a few hours to a week” (p. 2107). Additionally, a descriptive mixed-methods study by Sexton and Stephen (1991) found that parents who were supported in spending time with their baby after death regarded staff as being more helpful. In another mixed-methods study, only 61% of neonatally bereaved parents saw their baby after death; however, 81.5% considered this as an ‘essential’ experience and seeing the baby after death was significantly associated with higher satisfaction scores (Lasker & Toedter, 1994). This statistic stands in contrast with parents in the study who experienced perinatal loss between 16 and 26-weeks’ gestation; only 54.5% of these parents considered seeing the baby after death as an ‘essential’ aspect of their bereavement care (Lasker & Toedter, 1994). This difference between groups underscores the importance of differentiating

neonatal death from other forms of perinatal loss, as in this instance, the gestation of the baby and length of survival had a considerable impact on the needs and preferences of the parents.

It is also important to consider the outcomes for parents who were unable to spend time with their baby after death, or who chose not to. In several studies, parents who did not see their baby or child after death expressed feelings of regret in the months or years following their loss (Baughcum et al., 2017; Cacciatore & Flint, 2012, Hunt & Greefe, 2011). Indeed, Cacciatore and Flint (2012) reported that “When asked about regrets, there was an overwhelming response by parents who did not hold their child now wishing that they had” (p.164). Similarly, South African researchers Hunt and Greefe (2011) found that “None of the parents who had viewed their children’s bodies expressed any regret, in contrast to the parents who suggested that they had not found closure because they had not viewed their child’s body after they had died” (p.52). In addition, one Danish study found that failure to spend time with the baby after neonatal death was associated with higher scores on measures of both grief and trauma (Elklit & Gudmundsdottir, 2006). These findings imply that spending time with their baby after death is helpful for the majority of neonatally bereaved parents, and may be protective with regard to long-term psychological outcomes.

2.3.2 Participation in caregiving.

From the early 1980s evidence began to emerge that parents wished to be more actively involved in the care of their dying infants. For instance, White, Reynolds & Evans (1984) found that of 12 bereaved families, 11 described a desire to participate in the care of their dying infant. These findings have been consistent in more recent research, as several studies have found that participation in bedside care held significant meaning for parents (Abraham & Hendriks, 2017; Baughcum et al. 2017; Brosig, Pierucci, Kupst & Leuthner, 2007; Currie et al. 2016). Currie et al. (2016), conducted a descriptive study exploring parents' perceptions of end-of-life care in the NICU, with parenting emerging as a significant concern in this context:

It was important for participants to have the opportunity to “be a parent” in the NICU regardless of how much the parents could participate in the infant's care. One of the mothers described her time parenting in the NICU, ‘She (nurse) let me do anything I could possibly do that was mom-like...That was so exciting’ (p.481)

Similarly, bereaved parents in a longitudinal prospective study recalled parenting activities, such as holding or dressing the baby, with appreciation (Tan, Docherty, Barfield & Brandon, 2012). For the parents in this study, time spent with their baby as a family was considered especially important. The authors explain that knowing they had provided whatever love and comfort they could to their baby was crucial for the bereaved parents. This knowledge became a reassuring memory that parents could draw upon during their bereavement (Tan, Docherty, Barfield & Brandon, 2012).

Finally, Capitulo (2004) conducted an ethnographic study, recruiting 87 perinatally bereaved mothers who were involved in communicating via an online bereavement forum. She found that opportunities for parenting were vital, even after the baby had died. As Capitulo explains, “Parenthood is a lifelong role, even after the child is dead” (p.309). Although participating in care was described as potentially challenging for parents, researchers have consistently found that opportunities to provide care either during or after the infant’s death were important to bereaved parents in the wake of their loss.

Within the literature, a number of caregiving activities that may be important to perinatally or neonatally bereaved parents have been described. In particular, opportunities to engage in traditional parenting activities, such as changing nappies, dressing, and bathing their baby were consistently reported to be meaningful to participants across studies (Abraham & Hendriks, 2017; Baughcum et al. 2017; Brosig et al., 2007; Currie et al. 2016; Lisle-Porter & Podruchny, 2009; Meert, Briller & Thurston, 2005; Tan, Docherty, Barfield & Brandon, 2012). In the case of neonatal deaths, opportunities to parent the baby while they were alive were especially valued. However, providing care to the baby after death may also help parents to form meaningful memories with their baby (Lisle-Porter & Podruchny, 2009).

The significance of caregiving activities for parents may in part be related to identity formation. For example, Lathrop and VandeVusse (2011) performed a narrative analysis of the stories of mothers involved in a perinatal hospice program. They reported that examples of caregiving featured strongly in mothers’ narratives,

whether the baby was stillborn, or was live-born and died after birth. Providing care for the baby was described by the authors as a defining element of the concept of motherhood in these narratives. These findings indicate that in addition to supporting the development of memories, opportunities to participate in caring for their baby may help mothers to develop their identity as a parent.

A number of review articles also posit that specific parenting activities provide scope for parents to develop personally meaningful rituals that will help them to honour and remember their baby. For example, Kobler, Limbo and Kavanaugh (2007) described the use of bathing as a ritual, and explained that the thoughtful use of elements that stimulate the senses (such as sweet-smelling baby soap and soft, warm towels) “can create memorable moments, transforming an ordinary event into something unique for this child” (p.294). While some evidence exists to support the participation of parents in caregiving during and after the death of their infant, further research regarding the significance that specific caregiving experiences may hold for parents is warranted.

2.3.3 Bereavement photography.

Of all of the interventions designed to support parents in remembering their baby, bereavement photography is perhaps the most thoroughly studied. Multiple studies have found that parents who received photographs of their baby were typically grateful for these, while parents who were not offered photographs, or who declined them, later experienced regret (Alexander, 2001; Blood & Cacciatore, 2014; Cacciatore & Flint 2012).

Gold et al. (2007) reported that of the 60 articles included in their systematic review of hospital care for parents after perinatal loss, 26 specifically mentioned bereavement photography. They explain that “It is now common practice for hospitals to take photographs of infants after death. These are typically offered to the parents immediately or, if declined, offered again later or kept on file for a number of years” (p.1160). They add that across the qualitative studies included in their review, the majority of parents reported that having photos of their baby was important to them. Conversely, parents who did not have photographs described feeling regret. In addition to these findings, the authors also reported that 95-100% of parents across the quantitative studies included in the review described bereavement photographs as helpful. Indeed, bereaved parents in two studies rated bereavement photography as the most useful of the hospital-based bereavement services available (Gold et al., 2007).

Photographs may be useful for bereaved families; however, some researchers have reported that the quality and the content of the pictures is relevant. Specifically, in the case of neonatal loss, parents were more positive about photographs that were taken while their baby was alive (Harvey et al., 2008). Where photos were taken post-mortem, parents commented on the importance of timeliness, to ensure the photos were taken before changes to the baby’s appearance had occurred (Blood & Cacciatore, 2014).

Photographs that depicted the interaction between parent and child were considered especially valuable by parents, particularly where these captured instances of caregiving (Branchett & Stretton, 2012; Martel & Ives-Baine, 2014). Photos that were taken without medical equipment, such as endotracheal tubes, intravenous lines or monitoring were also found to be valuable (Harvey et al., 2008; Kavanaugh & Moro, 2006; Martel & Ives-Baine, 2014), especially as these often represented the parents' first unobstructed view of their baby. In addition, photos that were as close as possible to "normal" baby photos were found to be preferred by the parents (Martell & Ives-Baine, 2014). While the authors do not posit a reason for this preference, such photos may be both emotionally less confronting for parents and also easier to share with others, providing an opportunity for social recognition of the infant, and acknowledgement of the parents' loss. Finally, parents of multiples (e.g. twins, triplets etc.) stressed the importance of photographing the babies together. Parents who were unable to obtain a picture of their babies together expressed significant regret (Pector, 2004). While the quality and content of photographs should be considered, Blood and Cacciatore (2014a) noted that parents "overwhelmingly support postmortem bereavement photography when conducted sensitively, even if imperfectly executed" (p.1). Therefore, it seems that photographs should be taken and offered to families even if conditions are not ideal.

Bereavement photographs have been posited to serve several functions for bereaved parents. For example, a number of authors have described perinatal bereavement photographs as serving both as a way to confirm the baby's existence and a way to legitimise the parents' loss (Alexander, 2001; Blood & Cacciatore, 2014a;

Layne, 2000; Riches & Dawson, 1998). Blood and Cacciatore (2014), provide robust evidence on this point, drawing on their modified grounded theory research involving 181 bereaved parents. The authors found that the most commonly occurring concept related to the significance of photos in “helping parents identify their child as real and share that reality with others, in opposition to the stated or implicit invalidation of either the child’s existence or the legitimacy of their grief” (p.228). Similarly, Calhoun (1994) surveyed 23 parents who had experienced neonatal loss. She found that interventions that were perceived to provide “acknowledgement of the baby” such as bereavement photography were regarded as helpful by most parents. The findings of these studies indicate that bereavement photography helps to confirm the existence of the baby, and in doing so, helps to validate the grief experienced by perinatally bereaved parents.

Finally, photos may provide a trigger for memory and assist parents in processing their baby’s death (Alexander, 2001; Blood and Cacciatore, 2014a). Parents may fear that they or others will forget the baby (Capitulo, 2004); however, photographs act as an enduring record of the baby’s features and may provide reassurance that their baby was a real person who will not be forgotten. Bereavement photography is now a common practice in perinatal and neonatal end-of-life care and may act in a number of ways to help parents to cope with their loss.

2.3.4 Mementos and memory boxes.

While bereavement photographs emerged in the literature as the most common keepsake provided to bereaved parents, the majority of families across studies also received other items that were intended to act as mementos. Gold et al. (2007) report that of the 60 papers included in their systematic review, “Eighteen studies reported parents had collected memorabilia other than photos, and virtually all parents saw this as helpful” (p.1160). Within the literature, mementos that were frequently described included ink-based hand or footprints, or moulds of hand or feet made from plaster or clay (Baughcum et al., 2017; Cacciatore & Flint, 2012; Levick, Fannon, Bodemann, Munch & Ahern, 2017; Shelkowitz, Vassella, O’Reilly, Tucker & Lechner, 2015), items that had been in contact with the baby, such as blankets, hats or clothing (McGuinness, 2015), or a cutting of the baby’s hair (Cacciatore & Flint, 2012; Shelkowitz et al. 2015).

Numerous studies have found that the provision of mementos was an important element of care for parents experiencing perinatal loss (Baughcum et al., 2017; Cacciatore & Flint, 2012; McGuinness, 2015; Shelkowitz et al., 2015). For instance, Brosig et al. (2007) explored the needs and preferences of parents who had experienced the death of a baby between birth and one year of age. They report that:

Parents emphasized the importance of being able to bring things of the child home from the hospital, such as photographs, plaster casts of the child’s hands and feet, or clothing that the child wore in the hospital. This was

important especially since the parents were coming home without a baby. (p. 514)

Similarly, a mixed-methods study involving 30 perinatally bereaved parents reported that almost all participants regarded the provision of mementos, such as the baby's belongings, as helpful (Sexton & Stephen, 1991).

As with bereavement photographs, mementos may serve as evidence of the baby's existence, and may facilitate social recognition of infant loss (Uren & Wastell, 2002). Provision of mementos by staff may also be interpreted as a gesture of caring (Brooten et al., 2012; Lemmer et al., 1991). However, the significance that mementos hold for parents may be most evident in situations where they were desired but not provided. For example, Nordlund et al. (2012) reported that mothers in their study experienced distress when potential mementos were misplaced by staff, or when they had to argue with staff to keep items associated with their babies, such as hospital-supplied blankets or caps. Another study of perinatally bereaved parents found that "loss of any of those memories, or of the mementos that might crystallise them, such as photographs, locks of hair, handprints and footprints, was devastating" (Downe, Schmidt, Kingdon & Heazell, 2013, p.5). While parents who were able to collect and keep mementos found these valuable, lost opportunities to collect mementos were a significant source of regret for perinatally bereaved parents.

2.4 IMPACT AND SIGNIFICANCE OF MEMORY-MAKING IN THE LITERATURE

Memory-making interventions are utilised in paediatric and perinatal end-of-life care with the aim of improving parents' experience of bereavement. As described by Elklit & Gudmundsdottir (2006) "The rationale behind these practices is that active physical contact and the creation of visible mementoes will facilitate recovery from loss" (p. 317). However, findings surrounding the psychological outcomes associated with memory-making are mixed. For example, Elklit & Gudmundsdottir (2006) conducted a quantitative comparison of scores using both grief and trauma scales with memory-making activities in prenatal and postnatal deaths. The results are somewhat contradictory; some forms of mementos, such as a lock of hair or a footprint, were associated with higher degrees of distress, while others, such as a handprint, were found to not correlate with psychological wellbeing. The authors also report that "a larger number of physical mementoes was correlated with higher scores on all measures of distress in the PONL [postnatal loss] group" (p.322). However, it is debatable whether receiving or keeping mementos were causal factors in this research; rather it may be that parents who had formed strong psychological attachments with their baby before and after birth were both more likely to collect mementos and more likely to experience distress as a result of their loss.

Interestingly, several more recent studies have failed to find a significant association between the number or type of mementos and mental health outcomes in bereaved parents. For instance, in a study of 162 perinatally bereaved women, Crawley, Lomax and Ayers (2013) found no association between memory-making

activities and symptoms relating to depression, anxiety or PTSD. Similarly, Bennet et al. (2008) studied mental health outcomes in a sample of 91 women who had experienced a stillbirth or a neonatal death using validated measures of grief and trauma. Controlling for other factors, such as the number of surviving children, time elapsed since the loss, gestational age of the baby at death and the presence of other stressors, the authors report that “None of the ritual variables (seeing, holding, and taking pictures of the baby) were significantly correlated with the outcome variables” (p. 500). It appears that while the collection and creation of specific mementos may have some association with distress over time, for the majority of parents memory-making interventions did not increase the risk of adverse mental health outcomes.

While quantitative data on psychological outcomes remain somewhat mixed, there is considerable qualitative evidence that bereaved parents themselves place significant personal value on memory-making interventions. A number of authors have described memory-making as a powerful intervention with the potential to significantly impact on parents’ experience of loss. For example, one qualitative study with 25 perinatally bereaved parents found that:

The quality of memories was the anchor point for a good or a bad experience, with long-term and, often, unexpected consequences. Ensuring good memories and the collection of meaningful physical mementos was one of the most important things staff could do to help parents to deal with their situation. (Downe et al., 2013, p.5).

While this study explored the perceptions of parents experiencing stillbirth rather than neonatal death, a systematic review of bereavement care following neonatal loss indicated that neonatally bereaved parents place similar value on generating memories and collecting mementos (Harvey et al., 2008)

One of the major concerns around memory-making interventions is that reminders of the loss may act as a trigger for grief, while memorialising the infant or child may make the experience of loss more profound for some families. However, studies with bereaved parents suggest that holding on to grief may be an intentional aspect, rather than an unfortunate side-effect, of memory-making. For example, Kelly and Trinidad (2012) conducted a series of focus groups with perinatally bereaved parents and report that the majority of participants stated that they “want to grieve their children and do not want to forget, even if this causes or prolongs the pain of loss” (p.11). In their study of the spiritual needs of bereaved parents, Meert, Briller and Thurston (2005), similarly found that “Even painful memories served to keep parents connected to their child. A father explained, ‘I didn’t even want to forget the pain because I feel like if I lose it, then I’m kind of forgetting her’” (p.423). Finally, Umphrey and Cacciatore (2011) studied the narratives contained in communications between members of a bereaved parent support group. Parents in the study reported needing to keep their lost child’s memory alive. The authors report this was done in a number of ways, including the use of linking objects such as mementos or photographs. While mementos or photos that act to trigger memory may indeed occasion increased feelings of grief, it appears that parents may find value in this very aspect of memory-making.

2.5 SUMMARY AND IMPLICATIONS

A systematic search and critical review of the literature has revealed that few studies have explored memory-making as a bereavement intervention for parents experiencing the death of their newborn. Rather, the majority of studies used qualitative descriptive or mixed-methods approaches to describe parents' perceptions of neonatal or perinatal bereavement care. In these studies, memory-making frequently arose as an important theme. Although the impact of memory-making interventions on parents' long-term psychological wellbeing remains unclear, the existing evidence indicates that bereaved parents appreciate opportunities for memory-making, whether through spending time with their baby and caring for them, or whether through the collection or creation of photographs and other mementos.

While such research provides relevant insight into the needs of families, there is also a risk that these findings will simply be used to support a 'checklist' approach, in which parents are provided with a series of options as sanctioned by the evidence, and left to decide which memory-making activities they will accept. Instead, a thoughtful approach that takes into account the needs, wishes, values and beliefs of the parents, while acknowledging the need for support and guidance around memory-making is required.

Memory-making emerged as a recurrent theme in the paediatric and perinatal bereavement literature. However, few studies were identified that held memory-making interventions as their primary focus. As a result, the evidence underpinning

memory-making practices is scattered throughout the literature, impacting on its availability to clinicians and policy-makers. In addition, those studies that reported memory-making as one theme among many were restricted in the amount of detail provided. This has meant that evidence specific to memory-making practices has previously lacked the depth and quality required to guide clinicians.

It is also important to note that the majority of studies explored parents' perceptions or experiences of care following *perinatal* loss. Few of these studies provided sufficient detail to separate the data specific to parents experiencing a neonatal loss from the data arising from parents experiencing a stillbirth. It is likely that parents experiencing the death of a newborn would have many of the same needs and preferences as parents experiencing stillbirth. However specific interventions, such as spending time with the baby, or holding them, may have different implications for parents of a live-born infant, compared with parents who have experienced a stillbirth. Furthermore, the psychological outcomes associated with memory-making interventions could be significantly different between groups.

Currently, the evidence suggests that memory-making interventions are generally valued by bereaved parents. However, our understanding of *why* parents want or prefer specific memory-making interventions, and how parents perceive memory-making as affecting their experience of grief remains limited. The current study sought to address this gap, exploring the significance that memory-making interventions hold for neonatally bereaved parents and the impact that such interventions had on parents' experience of newborn loss. This study was conducted

with the aim of providing a substantive, or context-specific theory, to guide the use of memory-making interventions as a component of neonatal end-of-life care.

Chapter 3: **Theoretical Perspectives on Memory-Making**

3.1 INTRODUCTION

As described in the previous chapter, memory-making interventions have become increasingly common in clinical practice, and there is some evidence to suggest that such interventions are perceived as helpful by bereaved parents. However, there is currently a lack of coherent theoretical grounding to account for the significance that memory-making interventions may hold for bereaved parents, or to explain the potential impact of memory-making on parents' experience of grief. In this chapter, it will be argued that memory-making interventions may serve as a means of validating contested identities, both for the lost infant and the bereaved parent. It will also be posited that existing constructs, such as ambiguous loss and disenfranchised grief provide an important theoretical basis for memory-making interventions in perinatal bereavement. Finally, it will be argued that contemporary grief theories, which focus on transforming relationships with the deceased, and view bereavement as a dynamic and active process, may provide useful insights into the impact and significance of memory-making interventions for perinatally bereaved parents.

3.2 CONTESTED IDENTITIES

Perinatal loss is a unique form of bereavement in a number of ways. One of the distinctive challenges described in the theoretical literature relating to perinatal bereavement, is the contested nature of identity, both for the infant, and for the parent.

3.2.1 Contested personhood.

Malacrida (1997) explained that in perinatal loss, the physical death of the infant may be independent of “social death”, as the infant is often socially salient only to the parents. Godel (2007) also described this dilemma, arguing that babies who die during the perinatal period were potential, rather than actual, members of society and therefore lack a unique social identity. This lack of a social identity calls into question the personhood or ‘realness’ of the infant. This “realness problem” (p.321) was also discussed by Layne (2000) who used material culture analysis to explore the contested identities of infants who die during the perinatal period. She explained that in the context of perinatal loss the personhood which has been bestowed on the fetus is “revoked” and

the very people who have encouraged the mother-in-the-making to take on this role and may have participated with her in the social construction of her ‘baby’ often withdraw their support for these interrelated projects, and act as if nothing of any significance took place. (Layne, 2000, p.323)

Layne contended that this denial of loss challenges the work already undertaken by parents to construct an identity for the child, and in doing so, also belittles the significance of the loss. A similar deconstruction of identity was also described by Sawicka (2016) who engaged in a content analysis of online bereavement support threads in

Poland. Sawicka reflected that before the loss, pregnancies were viewed as a new life or a new member of the family, while after the loss, the infant was “deprived of this status as a life” resulting in uncertainty around “who or what had actually been lost” (p.234).

Whereas an older infant, child or adult would be recognised by others as a ‘real’ person who can and should be mourned, the infant who is stillborn or who dies within days of birth is arguably yet to be bestowed with a social identity that is salient to others beyond the immediate family. The baby is not considered to be a ‘real’ person, which also raises questions about the legitimacy of the identity and role of the parent.

3.2.2 Contested parenthood.

Several authors have identified that parents experiencing perinatal loss lose not only their child but also their identity as a parent to that child (Crawley, Lomax & Ayers, 2013; Malacrida, 1997; Robinson, Baker & Nackurd, 1999). Becoming a parent is a significant developmental milestone during adulthood and is a source of identity and purpose for many (Callister, 2006; Rubin & Malkinson, 2001; Stolberg, 2011). Cacciatore, DeFrain and Jones (2008) argued that for parents experiencing stillbirth, “their status as “parents” becomes complicated because there are no tangible signs of parenthood to affirm their roles” (p.443). The authors added that even in families with multiple children, the full scope of the individuals’ parenthood potentially becomes ambiguous, as the lost infant is often not acknowledged as part of the family by others. While these authors focused on parents experiencing stillbirth, a similar lack of evidence may exist for parents whose babies lived and died in the neonatal unit, and who may have been known by few outside the parental dyad.

The loss of an infant poses an existential and social conundrum for parents; is one still a parent if one does not have a baby? Using the theory of relational dialectics, Toller (2005) argued that bereaved parents may experience a “liminal identity” (p.46) as they experience the emotional aspects of parenthood in the absence of a physical child to parent. She concluded that this can “result in bereaved individuals feeling like a parent and not like a parent simultaneously” (p.46), impacting on the bereaved parent’s sense of identity. This sentiment was also expressed by Crawley et al. (2013) who described the role confusion experienced by a mother who has lost her infant. They explained that after a perinatal loss, the woman is at once a mother, having had a baby, and not a mother, being unable to physically hold or nurture her child. Understanding perinatal loss as a potential threat to identity is critical in appreciating the effect of such a loss on bereaved parents and the potential significance and impact of memory-making interventions for this population.

3.2.3 The role of memory-making in validating identities

As described by Henley and Schott (2008) the loss of an infant before or soon after birth is unique as a loss of someone important, “but of whom there are few or no tangible memories and often no memories that can be shared with other people” (p.327). In this context, memory-making interventions may serve an important role in establishing and legitimising the identity of the infant as a ‘real’ person. For example, a case series by Alexander (2001) highlighted the significance of bereavement photography, explaining that for perinatally bereaved parents, photographs served to validate their baby’s existence. Similarly, Godel (2007) argued that photographs of babies who were stillborn “help create a social identity for the baby, reconstructing the disrupted biography of the

family to include the dead child, thereby allowing him or her to be remembered, mourned and memorialized” (p.253). As described in the previous chapter, Blood and Cacciatore (2014) also discussed the significance of bereavement photography as helping parents to confirm the existence of the child and to share their child with others. Photographs may help to confirm the reality and identity of the infant and therefore help to legitimise the loss experienced by perinatally bereaved parents.

While perinatal bereavement photography may help to validate the baby’s existence, physical mementos such as clothing, personal affects, toys or even medical ephemera may act as further evidence of the baby’s reality, and identity, which endures once the baby is no longer physically present. Layne (2000) argued that perinatally bereaved parents use mementos “to assert their claim that a ‘real baby’ existed and is worthy of memory,” (p.322). Photographs and other mementos help to confirm the essential reality of the infant, and in doing so provide a means of developing a social identity that is both personally salient to the parents and able to be shared beyond the immediate family.

This ability to share mementos with others may also play a significant role in identity formation for parents. Layne (2000) reported that in addition to supporting the formation of an identity for the infant, sharing mementos may enable parents to receive social validation “that they are ‘real’ parents, deserving the social recognition this role entails” (p.322). Crawley et al. (2013) conducted a cross-sectional survey with 162 mothers who had experienced the stillbirth of their infant and examined the impact of sharing memories on psychological outcomes. In this study, memory sharing included discussing the child with others, sharing photographs of the infant, showing others’

keepsakes associated with the infant, or writing about the infant. The authors argued that sharing memories with others enabled women to adjust their identity to include their role as a mother more adaptively.

In addition to creating or collecting mementos, parenting activities may also serve to support identity formation, for both the infant and the parent. For example, a Cochrane review by Koopmans, Wilson and Cacciatore (2013) found that “Activities that support parents in developing a bond with their baby help create a sense of identity of the child” (p.5). Similarly, a study by Nuzum, Meaney and O’Donoghue (2018) identified that for parents who experienced a stillbirth, the personhood of the baby emerged as a significant concern. In part, parents in this study honoured the personhood of their baby by ‘parenting’ their baby in the time between birth and burial or cremation. Activities such as holding, bathing or dressing the infant, whether before or after death, may allow parents to step into their social role as parents, even if only briefly. These activities which typify parenting are critical to the development of a parenting identity.

A systematic review of bereavement interventions in neonatal end-of-life care, conducted by Harvey et al. (2008), found that “The widely endorsed practice of offering extended contact between parents and dying or deceased babies, and collection of mementoes, reflect contemporary models of grief in their affirmation of the reality of a child” (p.353). Supporting parents to care for their baby, and encouraging them to collect and create mementos, may help to establish a social identity for the baby as a ‘real’ baby while validating the role of the parents as ‘real’ parents. Although the majority of studies around memory-making interventions have focused on parents experiencing stillbirth, such research may still provide insight into the significance that memory-making

interventions hold for parents experiencing the death of their newborn, and the impact of such interventions on neonatally bereaved parents' experience of grief.

3.3 AMBIGUOUS LOSS AND DISENFRANCHISED GRIEF

3.3.1 Ambiguous Loss.

Closely related to the concept of contested identities, the theoretical construct of ambiguous loss may provide a useful perspective from which to examine perinatal loss and to appreciate the impact and significance of memory-making interventions for bereaved parents. Boss (1999) describes two fundamental forms of ambiguous loss. In the first form, "people are perceived by family members as physically absent but psychologically present" (Boss, 1999, p. 8). She provides examples of this type of ambiguous loss ranging from soldiers who are missing in action, through to parents who are absent from the family as a result of separation or divorce. In these forms of ambiguous loss, the lost person remains psychologically present in the mind of the mourner, despite being physically absent from their world. In the second form of ambiguous loss, the loved one remains physically present, but is psychologically absent; for example, in the case of severe dementia, where the body remains present, but the essential personality of the loved one is perceived as being absent (Boss, 1999). Boss argues that ambiguous losses are uniquely distressing, resulting in a form of "frozen" grief which "may never allow people to achieve the detachment that is necessary for normal closure" (p.10). While the concepts of detachment and closure have become increasingly contentious in the decades since this work was first published, the concept of ambiguous

loss may offer some explanation as to why particular forms of loss are so difficult to grieve in what western society deems a “normal” way.

Cacciatore, Defrain and Jones (2008) make a compelling case that perinatal loss may represent a form of ambiguous loss. In this instance, they argue that the infant is physically absent, however, remains psychologically present to one, or potentially both parents. In support of this concept, Lathrop and Vandevusse (2011) undertook a narrative analysis of interviews with mothers who utilised a perinatal hospice service. The authors found that “Having a strong bond of attachment and an identity as a mother, in the absence of a living baby, created a sense of unreality and a tendency for mothers to doubt themselves” (p. 259). The sense of ambiguous loss, characterised by the physical absence of the baby in the context of psychological and emotional presence, was clear in this group of mothers.

Conversely, McGee, Pettyjohn and Gallus (2018) conducted a phenomenological study with ten women, exploring their lived experience of miscarriage through the theoretical lens of ambiguous loss. Interestingly, they found that while some aspects of ambiguous loss fit with participants’ stories, such as a lack of socially approved bereavement practices, the central tenet of ambiguous loss as a form of “frozen” grief was not representative of these women’s experiences. While the concept of ambiguous loss may have some degree of fit or relevance in the context of perinatal loss, it is important that such theoretical constructs continue to be tested in the clinical setting. In particular, the relevance and fit of the construct of ambiguous loss require further exploration in the context of neonatal bereavement.

3.3.2 Disenfranchised grief.

Another theoretical construct that may help to explain the significance of memory making in perinatal bereavement is disenfranchised grief. Doka (1999) defines disenfranchised grief as “grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported” (p.37). Doka explains that each culture or society has established but often unspoken rules around grieving that dictate not only how grief can be expressed, and for how long, but also which losses are socially recognised. He explains that “these grieving rules may not correspond to the nature of attachments, the sense of loss, or the feelings of survivors and hence their grief is disenfranchised” (Doka, 1999, p.37).

Doka (1999) explicitly identifies perinatal death as a loss that may be perceived by others as “relatively minor” (p.38). Indeed, before the 1970s, perinatal loss was considered a “non-event”; the magnitude of the loss was unacknowledged by healthcare providers and the broader community, and parents were encouraged to move on and to have another child (Brownlee & Oikonen, 2004; Fenstermacher & Hupcey, 2013). Lewis describes the “rugby pass management of stillbirth ... the catching of a stillbirth after delivery, the quick accurate back-pass through the labor room door to someone who catches the baby” (as cited in Cacciatore et al., 2008, p.313). Stillborn or dying babies were quickly and quietly removed from the room in a misguided attempt to minimise the trauma experienced by the mother. Cacciatore (2010) comments that even today, stillbirth is “generally minimized and negated and is often treated as a non-event” (p.137). This lack of acknowledgement denies bereaved parents access to traditional

sources of support, and the rituals that give shape and meaning to socially recognised forms of grief.

The concept of perinatal loss giving rise to disenfranchised grief is well supported in the literature (Lang et al., 2011; Rando, 1986). For example, Wallerstedt and Higgins (1994) explained that in the case of perinatal bereavement, society fails to acknowledge the significance of the death of the infant as “people assumed because they never saw the infant, or that the infant lived for only a few weeks, that there was little parental attachment” (p.3). This experience of grief that is minimised or socially denied is borne out in more recent clinical research with perinatally bereaved parents. For example, Lang et al. (2011) reported that for couples experiencing a perinatal death, “the juxtaposition of their grief with society’s minimization often disenfranchises them from traditional grieving processes” (p.183). Similarly, Cacciatore et al. (2008) argued that infant deaths are rarely acknowledged in the same way as other child deaths and are therefore not legitimised as genuine bereavements. This lack of social acknowledgement is a hallmark of disenfranchised grief.

Indeed, Hazen (2003) points out that typical support systems, such as work colleagues, may fail to provide support in the context of a perinatal loss. She argues that “the grief of a parent who has suffered perinatal loss is doubly disenfranchised at work – grief in the workplace tends to be discounted, disenfranchised, or stifled; and the loss itself is often perceived as minimal” (p.149). This lack of support may extend beyond the workplace, to the parent’s broader social support network. For instance, in a study involving perinatally bereaved parents, Malacrida (1999) reports that there was a significant gap between parents’ perceptions of the significance of their loss and the

actual support offered by their friends, family and health care providers. A lack of social acknowledgement of the infant, and the resultant lack of recognition of the loss as a real and significant loss, may deprive bereaved parents of support, at the very time when it is needed most.

3.3.3 The role of memory-making in reducing ambiguity and validating loss

Few researchers have explicitly explored the relationship between ambiguous loss, disenfranchised grief and memory-making interventions. Giljohann and Mulvey (2004) described the background and outcomes of the “Treasured Babies Program”, which provided memory boxes for babies who had died in the perinatal period. They explained that gifts, such as memory boxes, acted to acknowledge and memorialise the baby, and in doing so, helped to validate parents’ sense of loss and grief. Nichols (1989) also wrote about disenfranchised grief in the perinatal period and argued that “Memorialisation may be particularly important when responding to disenfranchised loss. ‘The world must have tangible proof that my child lived and was cared for’” (Nichols, 1989, p.123). Nichols describes a wide range of memory-making practices, including creating mementos, providing care for the baby, and inviting others to meet the baby, that enable parents to step into their parenting role. Conversely, Nichols identifies that parents who are denied opportunities to spend time with their baby and to hold them or care for them may experience “a vagueness about who or what they have lost” (Nichols, 1989, p.125).

As described previously, supporting parents to care for their baby and encouraging them to collect and create mementos may help to establish a social identity for the baby and also validate the role of the parents. However, memory-making may also serve to legitimise the death of the infant as a real and significant loss, reducing the ambiguity of the loss and enabling bereaved parents to access social support.

3.4 CONTINUING BONDS

The concept of continuing bonds was first formally proposed by Klass, Nickman and Silverman in 1996. Continuing bonds denote the existence of an ongoing, internalised relationship between the deceased and the bereaved (Schut, Stroebe, Boelen & Zijerveld, 2006). Root and Exline (2014) explained that continuing bonds could take many forms, including reminiscence about the deceased, story-telling, keeping mementos, or internalising the values, beliefs, characteristics or preferences of the deceased. In addition, continuing bonds may be expressed through “interaction” with the deceased, such as feeling their presence or holding imagined conversations, or activities performed in honour of the deceased, such as altruism or memorialisation (Root & Exline, 2014).

Much of the research relating to continuing bonds has been focused on the outcomes associated with different expressions of continuing bonds (Boelen, Stroebe, Schut & Zijerveld, 2006; Field & Filanosky, 2009; Scholtes & Brown, 2015). Interestingly, Klass (2006) commented that the original objective of the continuing bonds theory was descriptive (i.e. people *tend* to maintain bonds with lost loved ones) rather than prescriptive (i.e. people *should* maintain bonds with their lost loved ones). The intent, Klass claimed, was to contest the notion that an ongoing relationship with the deceased

was inherently pathological. He argued, “When we ask whether maintaining bonds leads to healthy grieving, then, we are asking too simple a question” (Klass, 2006, p.845). As described by Field, Gao, and Paderna (2005), it is unlikely that a simple causal relationship exists between grief resolution and the expression of continuing bonds.

3.4.1 Continuing bonds in parental bereavement.

While research relating to continuing bonds has been conducted with many bereaved populations, the concept may be particularly useful in understanding the experience of bereaved parents. As described by Scholtes and Browne (2015) “Research on (continuing bonds) clearly demonstrates that continued connections with the deceased are maintained *especially by bereaved parents*” (p.76, emphasis added). Indeed, Klass’s original work arose from a 10-year ethnographic study of a bereavement support group for parents, describing the way bereaved parents found solace through maintaining a bond with their child after death.

Several more recent studies with bereaved parents of older children also suggest that parents maintain continuing bonds with their child after death. For example, Nuss (2014) conducted a grounded theory study with 18 bereaved parents and found that “redefining parenthood” was a central element of parents’ experience. The author explained that parents heal by

integrating the dead child into their inner self and into their social networks in a different way than when the child was alive. As time passes and the grief lessens, the relationship between the deceased child and parent changes, but there is still a connection between them. (p. e58).

Similarly, Harper, O'Connor, Dickinson and O'Carroll (2011) conducted a qualitative study of 13 bereaved mothers and found that parents maintained a relationship with their children through symbols, mementos or through acts of caring, such as tending the child's grave. Finally, Stevenson et al. (2016) found that bereaved parents actively worked towards maintaining a connection with their child, regardless of the child's age at death. They reported that parents in their study "often spoke about their continuing connection to their deceased child and their attempt to maintain the memory of their child" (p.658). The concept of continuing bonds has become increasingly common within the grief and bereavement literature. While the evidence surrounding the outcomes associated with continuing bonds becomes increasingly nuanced, it is important to recognise that such bonds appear to be a common element of bereavement for parents experiencing the loss of a child.

3.4.2 The role of memory-making in supporting continuing bonds.

Memory-making may support parents in maintaining continuing bonds with their child. In a phenomenological study of 28 bereaved parents, Woodgate (2006) found that memories were crucial as they allowed parents to maintain a relationship with their child after the child's death. Conversely, the authors argued that parents with fewer memories struggled to live without closure. Côté-Arsenault (2003) also studied the role of mementos in assisting parents to incorporate babies lost in the perinatal period into the family. She reported that in the absence of their living babies, parents found ways to maintain a sense of physical presence, "through concrete objects clearly and directly connected with the babies, something to touch, to see, or to hang on to" (p.29), rather

than connecting with symbolic items which others might not have associated with their baby.

Similarly, a study of bereaved parents' needs found that "Some parents told of the need for mementos to help them maintain connection with the deceased child" (Meert, Briller, Schim, Thurston & Kabel, 2009, p.721). Parents in this study specifically described tangible objects, such as clothing worn by the child, a blanket or stuffed toy that belonged to the child, or items such as a lock of hair, as helping to support this connection. The concept of mementos as part of a continuing bond between the infant and parent has been touched on in numerous studies. For example, Brosig et al. (2007) conducted a series of in-depth interviews with parents who had lost an infant before the age of one. They observed that all of the families recruited into the study endeavoured to keep the memory of their baby alive by displaying photographs or other mementos in their home. The authors explained that parents were adamant that:

Even though their children may have lived only for a very short time, their lives were not insignificant. These findings are consistent with more recent theories of grief which emphasize parents holding on to their relationship with their dead children as opposed to 'letting go'. (p.515)

In light of an increased understanding of the role of continuing bonds as a normal and potentially adaptive response to grief, memory-making may be seen as a useful element of bereavement care, helping to support the creation or maintenance of a continuing relationship with the lost child.

In addition to supporting continuing bonds between a parent and their child, mementos may also enable continuing bonds to be “collectively held” (Klass, 2006, p.851). In a qualitative exploration of women’s experience of perinatal hospice, Lathrop & VandeVusse (2011) found that “Most of the mothers described pictures or other mementoes of their babies displayed in their homes” (p25). By displaying these items in ‘public’ spaces within their homes, parents may also have been inviting conversation about their lost child, and in doing so creating and maintaining their child’s enduring biography.

Riches and Dawson (1998) describe the mementos of lost children as “objects of discourse”, describing “ways that photographs and other representations are used by bereaved parents in the painful task of establishing a ‘durable biography’ of their child” (p.122). The authors claimed that photographs serve to capture memories in a way that enables events not only to be remembered, but potentially reinterpreted, and for comfort and meaning to be sought. They argued that photographs act both as a focus for “internal conversation *with* the deceased, and as a vehicle for conversations between the surviving relatives and others *about* the deceased” (p.124). In this sense, photographs and mementos may support both internally held continuing bonds between parent and child, and enable that ongoing relationship to be shared with others.

3.5 DUAL PROCESS MODEL

In addition to the concept of Continuing Bonds, the Dual Process Model (DPM) of grief may provide useful insight into the unpredictable nature of each individual’s grief, using the concept of oscillation to capture the “dynamic and fluctuating” nature of grief

(Stroebe & Schut, 1999; 2010). The DPM identifies movement between “loss-oriented” and “restoration-oriented” processes as normal elements of coping with grief. As described by Balk et al. (2004), “loss-oriented coping refers to efforts to resolve the loss experience itself; restoration-oriented coping refers to efforts to master or adapt to challenges associated with the changes in life circumstances resulting from bereavement” (p. 500). According to Stroebe, Schut and Stroebe (2007) bereaved individuals:

confront and avoid stressors to do directly with the loss, such as going over death events (loss orientation) versus sources of secondary stress, such as dealing with finances (restoration orientation). (p.1968)

Stroebe and Schut (2010) added that that “An important postulation of the model is that oscillation between the two types of stressors is necessary for adaptive coping” (p. 278). This focus on oscillation allows for a less linear and more dynamic view of ‘normal’ grieving.

3.5.1 Dual Process Model in parental bereavement.

The DPM has been explored in a number of contexts involving bereaved parents. For example, Stevenson et al. (2017) explored 21 parents’ experiences of bereavement following the loss of children aged from birth to 19 years of age. They reported that parents’ emotional states and ways of coping oscillated over time. They explain that parents reported that “at times they wanted to actively process the events and experience the emotions related to the loss, whereas at other times they preferred to keep a distance and focus on getting back to ‘normal life.” (Stevenson et al., p.651). This oscillation between focusing on the loss and focusing on building a life changed by that loss is characteristic of the DPM conceptualisation of grief, as a dynamic and fluctuating

process. Indeed, Currie et al. (2018) recently conducted a qualitative descriptive study of parents' experiences of bereavement and coping after their baby had died in the neonatal unit. The authors used the DPM as a conceptual framework to underpin their analysis, as the model "incorporates the fluidity of the coping process that can occur with bereavement" (p.2).

3.5.2 Memory-making and the Dual Process Model

Stroebe and Schut (2010) specifically identify behaviours directly related to memory-making, such as looking at photographs of the deceased, as loss-oriented activities. Indeed, Currie et al. (2018) reported that while some bereaved parents become overly focused on loss-oriented processes, including consistently looking through their baby's memory book, more often "parents found it helpful to keep physical reminders of their infant and by remembering the infant through traditions supported by family and friends" (p. 7). The authors found that "Oscillation occurred between loss-oriented stressors such as reminiscing through physical reminders of their infant to restoration-oriented stressors such as staying busy with new projects and roles after infant death" (p.8). By enabling parents to spend emotional time and energy remembering their baby's brief life and death, mementos may provide a means for parents to engage with their loss.

More subtle examples of loss-orientation were apparent throughout the perinatal bereavement literature. For example, Kelley and Trinidad (2012) reported that parents in their study deliberately held on to the memories they had of their baby at birth, such as holding their baby, their facial features or the shape of their feet or hands "and yet they do so knowing that these memories also will trigger sadness. As one mother said, 'My

saddest memories are also the ones I cherish” (p.8). This concept of keeping the memory of the child alive was a recurrent theme and could be argued to represent a loss-orientation in bereaved parents.

Riches and Dawson (1998) made an interesting argument for photographs as an aide to both the “loss-oriented” and “restoration-oriented” elements of grief as proposed by Stroebe and Schut (2010). They explained that “photographs can provide an important prop both as an object of personal internal conversation with the deceased and as a vehicle for conversations between surviving relatives and others about the deceased” (Riches & Dawson, 1998, p.124). In this sense, photos that are privately viewed may assist with reflection on the loss and emotional expressions of grief, while the same photographs when shared may assist with “restoration-oriented” tasks, such as rebuilding or re-engaging in relationships with others.

The dual process model of coping with bereavement may contribute to understanding the impact and significance of memory-making for parents experiencing the death of their child in the neonatal unit. Being able to actively reflect on time spent engaging with and caring for the baby may be an element of loss-orientation, while tangible items such as photographs or mementos may provide an anchor-point for these reflections. At the same time, photographs and other mementos that can be shared with others may help parents in rebuilding their identity in the wake of their loss, or help them to renegotiate relationships that were disrupted by the loss. In this sense, memory-making may be viewed as an important element of both loss-oriented and restoration-oriented processes in bereavement.

3.6 A THEORETICAL BASIS FOR MEMORY-MAKING INTERVENTIONS

Despite an explosion in grief and bereavement theory over the past few decades, little theoretical development has occurred in the specific context of neonatal bereavement, and to date, few theoretical structures have been developed to underpin or guide bereavement interventions for parents experiencing the death of a newborn. However, a number of theoretical constructs and models have the potential to provide insight into the impact and significance of interventions such as memory-making in neonatal end-of-life care. The concepts of contested identities, ambiguous loss, and disenfranchised grief, as well as bereavement theories, such as continuing bonds and the DPM, each have the potential to contribute to understanding how memory-making might be significant for bereaved parents.

Furthermore, several of these constructs can be seen not only as compatible, but also potentially as synergistic. For example, the concepts of contested identities may help to explain why perinatal loss may result in disenfranchised grief. If the identity of the baby and the role of the parent is not socially acknowledged, then grief reactions cannot be socially recognised or socially supported, resulting in disenfranchised grief.

Concepts such as ambiguous loss and disenfranchised grief also share some commonalities. For instance, Boss (1999), argued that one of the reasons that ambiguous loss is so painful is that few rituals exist to support individuals experiencing an ambiguous loss. As their grief is not socially recognised through the traditional rituals of grieving, the bereaved person's feelings and experiences remain unvalidated. The lack of social acknowledgment or validation, and the absence of social ritual that can be observed in ambiguous loss, is also central to the experience of disenfranchised grief. Indeed, Golan

and Leichtentritt (2016) undertook a phenomenological study with ten women who had experienced stillbirth and found that participants experienced an internal sense of ambiguity around their loss. This sense of ambiguity was heightened when others questioned or minimised their loss. The need for acknowledgement of the death of the baby as a real loss, and the need for social rituals or interactions that honor that loss, are evident in both concepts of ambiguous loss and disenfranchised grief.

Finally, the DPM has been identified as being compatible with a broad range of other grief and bereavement theories. For example, in an early diagram presented by Stroebe and Schut (2001) to explain the DPM, the breaking or relocation of ties with the deceased was included as an element of “loss oriented” coping (p.396). This focus on severing ties with the lost loved one is an element of early conceptualisations of grief work (Rothaupt & Becker, 2007). In contrast, a similar diagram in a later paper by Stroebe, Schut and Stroebe (2007) explicitly included the *continuing* of bonds or ties as an element of loss-oriented coping. This addition implies that the theorists themselves came to see the DPM as being compatible with the theory of continuing bonds.

3.7 SUMMARY AND IMPLICATIONS

While there has been little research exploring memory-making in the context of neonatal end-of-life care, a number of existing theoretical structures could potentially be used to explain the impact and significance of memory-making for perinatally bereaved parents more broadly. Experiences of parenting one’s child and collecting or creating mementos may help to establish a social identity for the child, and in doing so, also help to legitimise the role of the parent. Furthermore, memory-making may reduce the

ambiguity associated with perinatal loss, and thereby improve parents' access to the social support typically available after the death of a loved one. Memory-making may also help parents to maintain bonds with their child that extend beyond death, allowing the child to be integrated into the parents' life moving forward. Finally, having memories of engaging with one's baby and providing care may enable parents to spend time reflecting on their loss, while sharing mementos and photos with others may support the reconstruction of identity for parents, and therefore act as an element of the restoration-orientation central to the DPM. While further empirical work is needed to understand how modern conceptualisations of grief and bereavement might work synergistically, it is argued that the concepts of contested identity, ambiguous loss, disenfranchised grief, and the theories of continuing bonds and the Dual Process Model could offer complimentary ways of understanding the significance and impact of memory-making for parents experiencing neonatal loss.

Chapter 4: **Methodology and Research Method**

4.1 INTRODUCTION

The intention in undertaking this study was to develop a substantive or local theory to guide practice around memory-making with bereaved parents in a neonatal unit context. Two broad research questions were used to guide this inquiry:

What significance do memory-making activities hold for parents experiencing the loss of an infant in the neonatal unit? And

What is the impact of memory-making activities on parents experiencing the loss of an infant in the neonatal unit?

These research questions were addressed using the grounded theory approach described by Corbin and Strauss (2008; 2015). In this chapter, I explore the history and philosophical basis of grounded theory as both method and methodology. The relevance of grounded theory methodology to this project is examined, with an emphasis on the rationale for selecting the approach espoused by Corbin and Strauss. In addition to an exploration of grounded theory methodology, a detailed description of the processes used within the current study is provided. The ethical dimensions of the study are presented, with an emphasis on the strategies used to minimise the risk of harm to potential participants. The methods used to recruit participants into this study are then discussed, and the sample for the study is described. The process of undertaking semi-structured interviews is outlined, and the analysis of interview data using constant

comparative analysis is explained. Finally, mechanisms for ensuring theoretical saturation are explored and methods used to ensure the scientific rigour of the study are described.

4.2 METHODOLOGY

4.2.1 Choosing Grounded Theory

Grounded theory has been described as “a systematic yet flexible methodology, designed to assist with the development of substantive, explanatory models grounded in relevant empirical data” (Hutchison, Johnston, & Breckon, 2010, p.283). Boychuck Duchscher and Morgan (2004) add that the overarching aim of grounded theory research is the discovery of theory:

that is faithful to the reality of the research area; that makes sense to the persons studied; fits the template of the social situation, regardless of varying contexts related to the studies phenomenon; adequately provides for relationships amongst concepts; and may be used to guide action. (p.606).

Grounded theory research has the potential to generate two forms of theory. Substantive theories are concerned with specific events or experiences occurring in everyday life, while formal theories are typically more general and “can be used to understand a wider range of social concerns and problems” (Corbin & Strauss, 2015, p. 63). The focused or narrow nature of substantive theory has been argued to lend it “usefulness to practice often lacking in theories that cover more global concerns” (Merriam & Tisdell, 2015, p.32). The capacity to develop a contextualised, substantive theory with immediate relevance to clinical practice was central to the decision to use grounded theory in favour of other forms of qualitative enquiry in this study.

Grounded theory has also been identified as being well suited to situations where little knowledge already exists (Engward, 2013; Schreiber, 2001). As described by Birks and Mills (2011), the processes inherent in the grounded theory method, including the cyclical nature of data collection and analysis “result in the generation of new knowledge in the form of theory” (p.17). Therefore grounded theory is most useful when employed in areas where little is known about the topic, and where the development of theoretical frameworks will have a clear benefit. While perinatal bereavement is the subject of increasing research attention, little is currently known about bereavement interventions, such as memory-making, in the context of neonatal loss. A grounded theory study was identified as having the potential to address this gap while making a significant and original contribution to knowledge in the perinatal bereavement field.

4.2.2 A brief history of Grounded Theory Methods and Methodologies

Grounded theory methods were first described in detail by sociologists Barney Glaser and Anselm Strauss in “The Discovery of Grounded Theory” [hereafter referred to as ‘Discovery’] in 1967. Grounded theory was developed as a response to what Glaser and Strauss dubbed “armchair theorising” (Corbin & Strauss, 2015, p.6). The authors noted a trend in sociology toward the development of theory based on apriori assumptions or ‘common sense’ with a few pertinent cases for illustration. Using grounded theory methods on the other hand, “one generates conceptual categories or their properties from evidence; then the evidence from which the category emerged is used to illustrate the concept” (Glaser & Strauss, 1967, p.23). The aim of grounded theory research was therefore to develop theory, which would “fit the situation being researched, and work when put into use” (Glaser & Strauss, 1967, p.106).

While 'Discovery' provided a justification for the development of the grounded theory method, and for the generation rather than verification of theory, there was arguably a lack of guidance to assist novice researchers in learning the procedures that constitute grounded theory (*cf.* Allen, 2003). In 1978 Glaser wrote 'Theoretical Sensitivity' in an attempt to explicate these procedures, while Strauss wrote briefly about these in a chapter of 'Qualitative analysis for social scientists' (1987). Strauss's approach was more fully explicated in the book "Basics of qualitative research: Grounded theory procedures and techniques" [hereafter referred to as 'Basics'], first published by Strauss and his former student Juliet Corbin in 1990.

Glaser responded to the publication of 'Basics' with an impassioned rebuttal, in which he claimed that Strauss had moved so far from the original premise of grounded theory as to have developed a separate method that he titled "full conceptual description" (Glaser, 1992). In particular, Glaser took exception to Strauss and Corbin's explication of coding processes, repeatedly arguing "that by using concepts such as 'axial coding' and 'coding paradigms' researchers would 'force' categories on the data instead of allowing the categories to 'emerge'" (Kelle, 2005, para. 19). This difference in approaches potentially points to significant disparities in the worldviews of Glaser and Strauss.

In addition to the methodological split between Glaser and Strauss, numerous alternative approaches to grounded theory have been described over the past 25 years. One of the most popular of these approaches is constructivist grounded theory, initially described by Kathy Charmaz. Charmaz challenges the notion of emergence, which is so fiercely championed by Glaser, arguing that "neither data nor theories are discovered.

Rather, we are part of the world we study and the data we collect. We *construct* our grounded theories through our past and present involvements and interactions with people, perspectives and research practices” (Charmaz, 2006, p.10). Within Charmaz’s constructivist approach, similar stages of coding to those described by Glaser are used, but with the intention of developing a “picture that draws from, reassembles, and renders subjects’ lives” (Charmaz 2003, p. 270). This approach arguably represents a departure from the intent of traditional forms of grounded theory, which holds the construction of theory that is grounded in the data as the primary aim.

While there are differences between the approaches described by Charmaz compared with those described by Corbin and Strauss, the most recent edition of “Basics” includes a clear recognition of the role of constructivism in grounded theory. Indeed, Corbin states that she agrees with the constructivist assumption that theories and their underlying concepts are “constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and lives, both to the researcher and themselves” (Corbin & Strauss, 2015, p.26). In the context of the current research, this acknowledgement of the constructed nature of knowledge, combined with a structured approach to developing theory offered by Corbin and Strauss, provided the best opportunity for making an original contribution to knowledge while shaping clinical practice.

4.2.3 Ontology and epistemology underpinning grounded theory methodologies

In describing his approach to grounded theory, Glaser claims that this approach is a “general inductive method, possessed by no discipline, or theoretical perspective, or data type” (Glaser, 2005, p.141). Indeed, Glaser argues that attempts to align grounded

theory research with any particular philosophical tradition reduce its inherent power as a method. However, Annells (1996) convincingly argues that language used in the original work of Glaser and Strauss, and later Glaser alone, demonstrates a post-positivist, objectivist orientation, with explicit directions given to aid the researcher “to come closer to objectivity” (Glaser, 1978, p. 8). In particular, Glaser’s insistence on emergence indicates a belief that there is an objective reality that is independent of the researcher, that will reveal itself if the researcher remains true to the grounded theory process.

This attempted philosophical agnosticism, and underlying objectivism, stands in stark contrast to the philosophical stance articulated by Corbin and Strauss. In describing the epistemological assumptions underpinning their approach, Corbin and Strauss (2015) explain that “This methodology’s epistemology has come to it in a two-step evolution, involving both the tradition of Chicago Interactionism and the philosophy of Pragmatism inherited largely from John Dewey and George Mead” (p.18). Corbin and Strauss (2015) provide a brief overview of both symbolic interactionism and pragmatism, highlighting the focus of both on the creation of knowledge through action and interaction, and the complex and evolving nature of knowledge over time.

Corbin and Strauss (2015) explicitly state that the researcher does not need to adopt a pragmatist or interactionist worldview to use grounded theory methods successfully. However, an understanding of the philosophical basis of the method assists the researcher in identifying whether their method that has a sound fit, both with the researcher’s personal epistemological position, and for the project in question. Corbin and Strauss (2015) draw on both Herbert Blumer’s Symbolic Interactionism and John Dewey’s Pragmatism, emphasising the complex, unpredictable, mutable and contextual

nature of human knowledge and interaction. Given the significant philosophical differences between approaches to grounded theory, a clear acknowledgement of the researcher's ontological and epistemological orientation is critical in determining which version of grounded theory is most suitable (Birks & Mills, 2011). The symbolic interactionist and pragmatic perspectives inherent in Strauss and Corbin's approach have resonance with my own world view. In particular, the concept that knowledge is provisional and socially constructed is in keeping with my own epistemological position as a clinician and researcher.

Perhaps more importantly, the assumptions derived from symbolic interactionism that underpin Corbin and Strauss's approach are also well suited to the research questions posed, and the context of this research. For example, symbolic interactionism focuses on small-scale social interactions. Many of the ways that parents create memories with their newborn require social interaction on a variety of levels. Furthermore, the emphasis on symbols, and the meaning that symbols hold for individuals, is a useful lens through which to explore the significance that memory-making interventions may hold for bereaved parents.

The position of the researcher is also a function of the philosophical assumptions inherent in the various approaches to grounded theory research. In keeping with an objectivist stance, Glaser can be seen to view the researcher as a neutral entity, who is "external to the process and is an observer rather than a creator or participant" (Levers, 2013, p.4). This expectation of objectivity has garnered criticism from some; for example, Bryant (2007) contends that:

the positivist stance of a neutral observer, gathering data about the world, from which theories somehow emerge is now so severely discredited that one of the few places in which one can find such unreconstructed positivism is in the work of some of those claiming adherence to GTM. (p.108).

Conversely, Corbin and Strauss identify the researcher as an active participant in the method rather than separate from the method, reflecting their subjectivist orientation (Annells, 1996). Indeed, Strauss and Corbin (1994), claim that the researcher is a “crucially significant interactant” (p.278) who can use their personal and professional knowledge and experiences to add richness and depth to data collection and analysis. Corbin and Strauss’ (2015) version of grounded theory was identified as appropriate given my own background as a clinician and researcher. Rather than viewing the professional knowledge of the nurse-researcher as a threat to emergence, Corbin and Strauss celebrate the emic perspective of the researcher as a potential source of theoretical sensitivity.

The epistemological assumptions which underpin the grounded theory approach described by Corbin and Strauss were identified as being more suited to the research question and better aligned with the world view of the student researcher than the post-positivist, objectivist assumptions underpinning the traditional Glasserian approach to grounded theory. In addition, Corbin and Strauss’ view of the researcher’s professional experience as a source of insight, rather than as an obstacle to be overcome, enabled the nurse researcher to draw on clinical experience in identifying salient elements of parents’ stories. Consequently, the grounded theory approach described by Corbin and Strauss was determined to be ideal for the current study.

4.2.4 Limitations of Strauss Grounded Theory.

Corbin and Strauss's approach to grounded theory was identified as an appropriate methodology for the current study. However, the methodology is not without its limitations or criticisms. In addition to Glaser's insistence that Strauss had developed a method that was divorced from grounded theory altogether, Corbin and Strauss have also been criticised as being overly rigid in their approach to grounded theory. Indeed, Melia (1999) worried that "the procedures are getting in the way; the technical tail is beginning to wag the theoretical dog" (p.376). Similarly, Heath and Cowley, (2004) raised concerns that complex rules and coding paradigms described in earlier iterations of Corbin and Strauss's approach may be used "at the expense of heightened sensitivity and insight" (p.146). However, Corbin and Strauss have responded to this criticism in their more recent works, modifying their approach and encouraging researchers to view their data analysis techniques as suggestions rather than commandments (Cooney, 2010; Corbin & Strauss, 2015). This balance between structure and flexibility afforded by the evolved version of grounded theory provides scope for creativity while ensuring rigour and trustworthiness. The issues of rigour and trustworthiness specific to this study will be described in more detail later in this chapter.

4.3 RESEARCH DESIGN

4.3.1 Human Research Ethics

A key concern for researchers exploring bereavement is the burden of risk versus benefit and the potential to cause participants undue distress. This concern can lead researchers and research committees to question whether it is ethical to conduct

research with bereaved individuals who may be viewed as being vulnerable (Dyregrov, 2004; Hynson, Aroni, Bauld & Sawyer, 2006; Parkes, 1995). As elucidated by Parkes (1995) however, “It is unethical to introduce services for the bereaved that are not well founded and evaluated” (p.171). Given the dearth of evidence around memory-making interventions, and in particular, the impact of memory-making activities in the context of neonatal end-of-life care, it is an ethical imperative that this research is undertaken.

Furthermore, refusing the bereaved an opportunity to become involved with research on the grounds of protectionism may contravene basic ethical principles such as justice and respect for autonomy (Hickman, Cartwright, Nelson & Knafl, 2012). For this reason, it was considered essential to undertake research into memory-making in neonatal end-of-life care, while putting in place mechanisms to minimise the risk of harm to bereaved parents participating in the study. The following section will describe the practices used to safeguard the privacy, dignity, and wellbeing of participants.

Approval for the study.

Before commencing this study, approval was sought and obtained from the University of Melbourne Behavioural and Social Sciences Human Ethics Sub-Committee (ID 1443185.1, Appendix A). Given the potentially distressing nature of this research protection of participants from harm was of paramount concern. Participants in this study were protected both through the adherence to standards common to human research ethics, such as informed consent and protection of privacy, and the use of specific

strategies such as distress protocols, and the provision of support for participants during and after their involvement with the project.

Informed consent.

All participants in this study gave written consent for their involvement, signing a consent form (see Appendix B). Consent was also confirmed verbally at the beginning of each interview, at which time participants were reminded of their right to withdraw from the study at any time. However, given the sensitive nature of the topic and potential vulnerability of participants, there remained some risk that individuals may have agreed to participate without a full understanding of what was required. To ensure informed consent is genuine, Parkes (1995) suggested that researchers provide potential participants with clearly written information statements, that can be read at the participant's leisure and discussed with significant others. For this reason, individuals who made contact with me to express interest in the study were sent a plain language statement (PLS) (see Appendix C), either via email or post, and were encouraged to contact the student researcher with any questions or concerns. Before each interview, I confirmed that the participant had received and read the PLS, and asked whether they had any further questions.

Consent was also obtained to continue with the interview when participants became tearful or demonstrated other signs of distress. This renegotiation of consent has been described as "process consent" that requires "the immediate renegotiation of consent as circumstances change or unexpected events occur during the interview" (Kavanaugh & Ayres, 1998, p92). In this way, I remained responsive to the needs of the individual, promoting autonomy while minimising the risk of harm.

Protection of privacy.

As described by Kaiser (2009) a unique challenge for qualitative researchers is maintaining confidentiality while providing rich and detailed accounts of personal and interpersonal interactions. In particular, there is a risk that despite the removal of identifying data (such as names, ages and geographic locations), “deductive disclosure” may occur. Kaiser (2009) explains that deductive disclosure “occurs when the traits of individuals or groups make them identifiable in research reports” (p.1632). In the current study, rare diagnoses or unusual circumstances may have made some infants or their families identifiable to the staff who had cared for them, or to health professionals who had discussed their care in other forums. In addition, the relatively small number of participants recruited into the study increased the risk of deductive disclosure. For this reason, participants were informed that efforts would be made to protect their identity, but were also made aware of the risk of deductive disclosure within the plain language statement.

Additionally, the audio-recording of interviews has been identified as a potential threat to confidentiality, as the voice is a biomarker that may be used to identify the individual (Meert et al. 2008). In the current study, the interviewer was responsible for transcribing the audio-recorded interviews, with de-identified transcripts being made available to co-investigators as needed for quality control purposes. At the completion of data analysis, digital audio files were erased, while de-identified copies of the transcripts were stored in password protected files in the student researcher’s personal computer. Demographic data and signed consent forms were stored separately from the data, in a locked filing cabinet in a staff-only area on the university campus. Copies of the de-

identified transcripts will be retained for no less than five years following the final publication arising from this study.

Managing participant distress.

As noted earlier, given the emotive nature of the topic, it was anticipated that participants might experience distress, either during or after their participation in the project. Before commencing each interview, participants were reminded of their right to withdraw from the study, and were also encouraged to either pause or terminate the interview, should they feel overwhelmed or distressed. The interviewer monitored the tone and content of participants' speech, as well as para-verbal cues, such as pauses or sighs, to identify signs of distress. In those interviews conducted in-person or via Skype, attention was given to participant posture, gestures and facial expressions that might have indicated escalating distress. Similarly, during telephone interviews, the interviewer monitored for sounds of crying, hesitation or any other indication that the participant was becoming increasingly distressed.

While every participant demonstrated some signs of distress, it must be acknowledged that expression of emotion is a normal component of grief and that opportunities for such expression can be therapeutic. Parkes (1995) explains that "the interviewer need not attempt to block or inhibit such spontaneous expressions. Bereaved people expect the discussion of emotionally distressing events to be painful and may resent being told to calm down" (p. 175). Similarly, Dyregrov (2004), reported that bereaved parents found it was "to a greater or lesser degree painful" to talk about their loss (p.391). However, despite this pain, no parent regretted their participation and all described their experience of research participation as positive or very positive overall .

The work of both Parkes and Dyregrov indicates that parents are likely to anticipate that engaging in research may exacerbate feelings of grief, but that they may wish to participate despite these feelings. For this reason, interviews were not automatically ceased when participants demonstrated signs of distress; rather, the interviewer offered participants the choice of continuing or ceasing the interview, thus respecting the autonomy of the individual. In this study, all participants elected to continue with their interview and none expressed significant distress at the completion of the interview.

Distress protocol and support for participants.

Hickman et al. (2012) describe the plans used by many researchers to support or protect participants when exploring end-of-life issues. They describe such plans as ranging from provision of the contact details for community services, to direct referral to mental health professionals. Draucker, Martsof and Poole (2009) provide a more detailed description of distress protocols, that may include:

(a) Employing interviewers who are trained to manage psychological distress, (b) consistent monitoring of participants' emotional reactions, (c) providing frequent breaks during stressful data collection procedures, (d) debriefing, and (e) providing information on available psychological or social services. (p.343)

A similar distress protocol was put in place prior to conducting the current study to minimise the risk of harm to participants.

The first component of the distress protocol was ensuring that interviews were conducted by an appropriately trained individual. In the current study, I (the student researcher) conducted each of the interviews. I have previously undertaken qualitative interviews around grief and loss related topics and have also undertaken training in

qualitative interviewing techniques. I also have extensive experience in paediatric and neonatal nursing, including palliative care of infants and children. These experiences meant that I was adequately prepared to monitor the emotional state of participants and to respond to distress should it have emerged. As described previously, participants were offered an opportunity to pause or discontinue the interview if they became tearful or demonstrated other signs of distress. However, no participant accepted this offer; each wished to continue with the interview.

Participants in this study were also offered an opportunity to debrief, both immediately after the interview, as well as via telephone the following day. As described by Baumbusch (2010), parents participating in emotive research require an outlet for further discussion of issues raised during qualitative interviews. Therefore, at the close of each interview participants were asked if they would like the researcher to contact them the following day. This call was intended to enable participants to share any concerns arising from their experience of the interview, as well as providing an avenue for follow-up if concerns arose during the interview about the individual's mental health or wellbeing. None of the bereaved parents interviewed for this study expressed ongoing distress at the conclusion of their interview, and all participants declined the follow-up telephone call when offered.

Finally, participants in the current study were provided contact details for several support services designed for bereaved parents. Those participants who had been recruited via support services were encouraged to remain in contact with their existing service, while 24-hour helpline numbers were also made available as part of the plain language statement. Participants were also provided with the contact details for the

student researcher and the office for research integrity if they had any concerns or questions about the research.

Making contact with bereaved individuals.

Participants in the current study were made aware of the research project through the newsletters and social media sites of organisations that provide support or other services for bereaved parents. Indirect written contact with potential participants was recommended by Meert et al. (2008), who conducted an exploratory study of ethical and logistical issues in paediatric bereavement research. The authors claimed that privacy can be promoted by providing a written description of the project and an invitation to participate. Meert et al. argued that this process allows “potential participants to consider the research before being approached directly by an investigator” (p.445). As study information was placed in newsletters and on social media sites, no direct contact with the researcher was required, unless initiated by the potential participant. This recruitment strategy reduced the potential for coercion.

Furthermore, in opening a support organisation newsletter, or clicking on a bereavement-related social media site, individuals were aware that they would be confronted with information around grief and loss. Making initial contact with parents in this way reduced the risks of causing distress with unsolicited and unexpected contact from researchers. Simultaneously, it was anticipated that this strategy would reduce the risk of initiating contact with parents on “personally meaningful dates” (Hickman et al., 2012), such as the anniversary of the baby’s birth, diagnosis or death.

Benefits of research participation.

A key component of ethical decision making in research is the balance between risks and benefits, both individually and to the broader community. As such, it is vital that the risk to the individual participant is minimised, but also that the potential benefits of research participation are considered. Hynson et al. (2006) investigated bereaved parents' perceptions of research participation. They found that "although the majority of parents primarily chose to participate for altruistic reasons, many described the research process as personally beneficial" (p.805). The authors explain that during the interview, 70% of participants volunteered altruistic motivations for participation, such as enhancing service provision to other families. In addition to altruism, over one-third of participants spontaneously reflected on the personal benefits they had obtained through research participation. In particular, families valued the opportunity to tell their story and to express their grief in a socially acceptable way.

Similarly, Dyregrov (2004) and Lowes and Gill (2006) found that parents engaging in bereavement research valued the ability to relate their stories and hoped that their participation might help others. Indeed, Dyregrov argued that "instead of causing distress, research may be educational, enriching, therapeutic or empowering for vulnerable populations" (p.392). Several participants in the current study offered spontaneous comments regarding their experience of research participation after the interview was ceased and the recording had ended. In all cases, these comments indicated that bereaved parents valued the opportunity to discuss their baby and to describe their experience of loss.

4.4 SELECTION CRITERIA

The aim of this study was to investigate bereaved parents' attitudes and responses to memory-making activities offered in the context of acute neonatal end-of-life care. Therefore, to be considered for the study, participants needed to be parents who had experienced the death of their infant in a neonatal unit, special care unit or neonatal intensive care unit. This excluded parents whose infant had died in the delivery room, as well as parents who had experienced a stillbirth. For the purposes of this study, the term 'parent' was used to indicate any individual who identified himself or herself as a parent or primary caregiver of an infant who had died in an acute neonatal care setting.

Consideration was given to restricting participation based on time elapsed since the loss, as there was concern that parents who had experienced a recent loss may have been particularly vulnerable. A decision was made not to restrict participation on this basis for several reasons. Firstly, to be included in the study, participants were required to initiate contact with the researcher. It was deemed unlikely that individuals who felt too distressed to participate in bereavement research would initiate such contact. Secondly, limited evidence was found to suggest a specific period after the loss during which parents were likely to be more or less vulnerable. This lack of evidence meant that any time restriction would have been, to some extent, arbitrary. Finally, it was felt that while bereaved parents are a vulnerable group, restricting access to research participation would fail to respect the individual's right to self-determination and as such was not ethically justified.

4.5 RECRUITMENT

Information about this study was distributed by several parental bereavement support organisations or bereavement services, via social media pages, websites or newsletters. SIDS and Kids (now Red Nose), SANDS, Compassionate Friends Victoria, Compassionate Friends New South Wales, Miracle Babies, Heartfelt and Pillars of Strength each supplied information to families, including the aim of the study, the inclusion criteria, and the student researcher's contact details (see Appendix D for example). This approach enabled parents to contact the student researcher for further information, without the risk of coercion to participate.

4.6 SAMPLING

In this study, purposeful sampling was used initially, followed by theoretical sampling. As described by Henwood and Pidgeon, (2003) although grounded theorists emphasise theoretical sampling when describing their studies, the selection of initial informants or cases is typically based on rich or extensive experience of the phenomenon, environment, or process under investigation. In the current study, the initial informants were individuals with rich experience of the phenomena of interest. Both the first and second participant had undertaken volunteer roles providing support to other bereaved parents, in addition to having experienced the loss of their own babies in the neonatal unit setting. Analysis of these initial interviews yielded a number of important concepts, which were used to guide future sampling decisions, both around the selection of participants, and around the sampling of incidents within the data. This process of using data to guide subsequent sampling decisions is described as theoretical sampling.

Glaser and Strauss (1967) define theoretical sampling as “the process of data collection for generating theory, whereby the analyst jointly collects, codes and analyses his data, and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (p.205). This cycle of data collection and data analysis allows the researcher to sample based on the developing theory, rather than on predetermined criteria. Indeed, Corbin and Strauss (1990) argue that the traditional approach of extensive data collection followed by systematic analysis “violates the foundations” of grounded theory and that alternation between data collection and data analysis is central to the efficacy of the grounded theory method (p.6). Corbin and Strauss (2008) explain that theoretical sampling enables the researcher to maximise the development of concepts in terms of variation, properties, and dimensions, and to uncover relationships between concepts and categories. In this sense, the aim of theoretical sampling is to produce well-developed and interrelated categories, to form a robust theory of the phenomenon or process of interest.

As an example of theoretical sampling within the current study, analysis of the initial three interviews revealed that all three parents had less than 24 hours between the birth and death of their baby or babies, limiting opportunities for memory-making activities while the baby was living. As this appeared to have had a significant influence on the parents’ experience of memory-making, the student researcher sought to interview parents who had more time between the birth and death of their baby for comparison. The subsequent four participants had between four and 16 days with their living baby, with one family taking their baby home for several days before readmission to the neonatal unit. Analysis of these subsequent interviews revealed that parents who had

spent longer in the neonatal unit with their baby were typically offered more opportunities for memory-making.

Gender also emerged as a potential factor in parents' responses to memory-making. The first seven participants were bereaved mothers, several of whom commented that their baby's father responded differently to memory-making activities, photographs or mementos than they had themselves. The student researcher then actively sought to interview bereaved fathers, approaching 'Pillars of Strength', an organisation designed to support fathers experiencing loss. Interviews with fathers revealed some interesting variation in existing concepts and categories, although few new concepts were identified in these interviews.

Finally, eight of the first 10 participants mentioned "Heartfelt", a not-for-profit bereavement service that offers photography for families with seriously ill or dying infants or children. Participants who had access to Heartfelt services spoke in detail about the value of the photos they had received, while two of the eight parents commented that they wished such a service had been available at the time of their loss. For this reason, the Heartfelt organisation was contacted and agreed to post information about the study on their social media page for bereaved parents to access. Interestingly, not all of the parents recruited via the Heartfelt social media page had been recipients of Heartfelt's services; as with families attending more traditional support organisations, these families differed widely in their experience of memory-making in the neonatal setting.

The decision to recruit via Heartfelt not only allowed exploration of a theme that had developed from the data but also served to enhance the rigour and credibility of the theoretical model developed. While the intention of using bereavement support

organisations as a source of potential participants was to minimise the risks to participants inherent in direct and unsolicited contact, it must also be acknowledged that this had the potential to create bias in the data. It is possible that a help-seeking population, such as those engaged with counselling-based support organisations, hold different perceptions and preferences regarding memory-making than those who are not. Conversely, a number of the individuals recruited via Heartfelt were not engaged with other support organisations, providing an alternative perspective on memory-making in neonatal end-of-life care.

In total, these recruitment strategies lead to contact with 28 bereaved parents. Of these, eight parents did not meet the inclusion criteria (the baby was stillborn or did not die in a neonatal unit), while two parents made contact to express interest in the study but did not reply to follow-up emails to establish a time for an interview. A total of 18 parents participated in semi-structured interviews. A description of the final sample is provided below.

4.6.1 Description of the Sample

The following table (Table 1) summarises the characteristics of the sample. More mothers (13) than fathers (5) participated in the study, and most babies were born prematurely with only four infants born at term. The majority of babies lived between one and seven days; however, one baby died within 2 hours of birth while another survived 13 weeks. Average time elapsed since the loss was six years (range 6 months to 17 years).

Table 1: *Participant Characteristics*

Interview Number	Parent number	Mother, Father or both	Year of birth	Gestation of baby at birth	Age of baby at death
1	1	Mother	2007	24 weeks (twins)	Both at 1 day
2	2	Mother	2009	26 weeks	1 day
3	3	Mother	2010	32 weeks	2 hours
4	4	Mother	2015	29 weeks	4 days
5	5	Mother	2010	Term	16 days
6	6	Mother	2015	28 weeks	6 days
7	7	Mother	2003	28 weeks (twins)	1 baby at 6 days
8	8	Father	2016	Term	7 days
9	9	Father	2010	26 weeks	3 days
10	10	Mother	2016	Term	4 days
	11	Father			
11	12	Mother	2006	27 weeks	18 hours
12	13	Mother	2004	Term	5 days
13	14	Mother	1999	24 weeks	15 days
14	15	Mother	2009	31 weeks (twins)	1 baby at 13 days
	16	Father			
15	17	Father	2014	Term	13 weeks
16	18	Mother	2015	24 weeks	7 days

4.7 DATA COLLECTION

4.7.1 Interviews

Numerous sources of data may be used alone, or in combination, to develop a grounded theory (Corbin & Strauss, 2015, p37). Long semi-structured interviews were used to collect data in the current study. Semi-structured interviews are uniquely flexible, offering sufficient structure to enable exploration of research questions while allowing participants the freedom to offer new insights into the subject at hand (Galletta, 2013;

Ryan, Coughlan & Cronin, 2009). Semi-structured interviews are typically conducted using an interview guide that contains broad questions about the research topic (Baumbusch, 2010).

In the current study, the initial interviews were conducted using a guide with broad questions about parent's experience of memory-making (Appendix E), however, additional prompts were used as needed to clarify or explore concepts raised by participants. During early interactions with the parents to arrange an interview time and to obtain consent, parents typically discussed their baby by name. However, in instances where the name of the baby was not mentioned by parents, the student researcher asked about this as part of explaining the interview process to the parent. This ensured that the baby was treated as a unique individual; an approach recommended by multiple studies involving perinatally bereaved parents (Downe et al., 2013; Gold, 2007; Henley & Schott, 2008).

Each interview commenced with the same opening prompt: "tell me a bit about your baby (name)". The intention of this initial prompt was to ensure that parents had an opportunity to share things they felt were important while allowing the student researcher to demonstrate a genuine interest in the baby, and in the parent's story. In response to this opening prompt, parents typically shared information about the pregnancy, the delivery, and about their realisation that their baby might not survive. These contextual conditions had the potential to influence parents' experience of memory-making in numerous ways.

In keeping with the tenets of the grounded theory method, the interview guide evolved throughout the study, based on the need to explore and “fill-in” nascent categories, and to verify or expand on previously identified themes with new participants. To this end, the interview guide was updated after each interview, to ensure data collection was driven by the concerns of participants, and to facilitate theoretical sampling of incidents within the data. For example, when caregiving activities emerged as a significant aspect of parents’ experiences within the first few interviews, a specific prompt was added to check this emerging theme against the experiences of new participants. In this sense, participants guided the inquiry; a process that ensures that the emerging theory is grounded in the data and enhances credibility (Cooney, 2011).

To minimise the burden on participants and to allow data collection from individuals living in rural or remote locations, a choice of face-to-face, telephone or videoconference (Skype) interview formats was offered to participants. Skype is a VOIP (voice over internet protocol) program that allows synchronous audio and visual communication using a smartphone, computer or tablet. Deakin and Wakefield (2013) describe their respective use of Skype as a medium for qualitative interviews in doctoral research. They argue that while face-to-face interviews have been the “gold standard” in qualitative interviewing for decades, advances in technology are offering alternative approaches that overcome some of the practical and logistical issues inherent in interviewing a geographically dispersed sample. Skype was selected as a platform as it is free to download, and is relatively user-friendly. While all participants in this study were offered the option of a Skype interview, only one couple chose to be interviewed in this way; instead, telephone was the most commonly selected interview modality.

The relative risks and benefits of telephone interviews have been well described. In particular, the loss of visual cues, such as facial expressions and body language, have been discussed as a potential disadvantage to telephone interviewing (Novick, 2008; Opdenakker, 2006). Some researchers have also described increased difficulty in developing a rapport with participants during telephone interviews compared with interviews conducted in person, although this is contested by others (Oltmann, 2016). Conversely, telephone interviewing has been identified as a potential means for increasing research participation in remote and rural populations, as well as those with limited mobility or access to transport (Opdenakker, 2006). Telephone interviewing was also identified as less resource intensive, both in terms of time for the student researcher and participant, and in terms of travel related expenses.

Interestingly, several participants who were offered a face-to-face interview on the basis of geographical location opted for a telephone interview instead. This choice may reflect the emotive nature of the topic. As described by Elmir, Schmied, Jackson and Wilkes (2011) "Telephone interviews may be well-suited to potentially sensitive topics because this technique provides participants with the opportunity to disclose intimate and closely held experiences without feeling uncomfortable" (p.13). Indeed, Ward, Goot & Hoare (2015) conducted a grounded theory study utilising semi-structured telephone interviews and asked participants to describe their experience using this means of data collection. Participants were positive about their experience overall and described feeling less inhibited and less subject to judgment during a telephone interview when compared with traditional face-to-face interview approaches. In the current study, a total of 10 interviews were conducted via telephone (including one couple), with five face-to-face interviews and one Skype interview (also a couple).

4.7.2 Transcribing

Immediately after each interview, the student researcher listened to the audio recorded interview in its entirety, making notes about the participant's tone, use of language, and emotional cues, and recording any purposeful gestures or changes in body language noted during face-to-face interviews. These notes were kept alongside field notes, which were documented before and during the interview. The researcher then transcribed the recording verbatim, including notes that indicated long pauses, changes in tone, and para-verbal cues, such as sighing, crying or laughing. After transcription, the entire recording was listened to a second time, and any inconsistencies between the transcript and recording were corrected.

4.8 DATA ANALYSIS

4.8.1 Theoretical sensitivity

As described by Glaser and Strauss (1967) the term 'theoretical sensitivity' denotes the insight that the researcher has into themselves, others, and the topic under investigation. Chamberlain-Salaun, Mills and Usher (2013) argue that theoretical sensitivity allows the researcher to identify nuances in the data, to "reconstruct meaning from data generated with participants" (p.7) and to determine the salience of data to the developing theory. According to Corbin and Strauss (2015), theoretical sensitivity may be developed through several means, including the use of technical and non-technical literature, as well as professional experience. However, the authors also caution that all insights arising from the literature or professional experience must be held up against the data to ensure that the developing theory remains firmly grounded in the data.

A number of sources of theoretical sensitivity were drawn upon in the current research. My own professional experience with bereaved parents in the neonatal setting was foremost among these. This experience enabled me to identify both common and uncommon examples of memory-making in the neonatal care context. Furthermore, professional experience allowed me to separate elements of the parents' stories that reflected a general experience of receiving care in the neonatal unit from aspects unique to memory-making and bereavement.

A brief review of the literature was also undertaken before the study, to establish the gaps in the literature and to ensure that the topic under investigation was not already well understood. While efforts were taken to avoid substantial and critical analysis of literature specific to the topic, broad reading around loss and bereavement provided some useful insights as to how the loss of a newborn may be both similar and distinct from other forms of loss. Throughout the study, memos were used to track thinking and to ask questions of the data. The use of memos ensured that neither concepts derived from professional experience, nor concepts from the literature, were 'forced' on the data; rather, every concept and category had to earn its place in the eventual theory based on its recurrence and significance within the data. The process of memo writing is explored in more detail later in this chapter.

4.8.2 Constant comparison

Corbin and Strauss (2008) explain that the constant comparative method requires that:

data are broken down into manageable pieces with each piece compared for similarities and differences. Data that are similar in nature... are grouped

together under the same conceptual heading. Through further analysis, concepts are grouped together by the researcher to form categories. (p. 7).

Boeije (2002) claims that alongside theoretical sampling, the constant comparative method is central to the analytic process within grounded theory research. She contends that “By comparing, the researcher is able to do what is necessary to develop a theory more or less inductively, namely categorizing, coding, delineating categories and connecting them” (p.393). Strauss and Corbin (1990) argue that this constant comparative analysis helps protect against bias, as the researcher is constantly holding their assumptions up against the data. They also claim that constant comparison enhances precision and consistency, as it encourages the researcher to group like concepts, and only like concepts, together without exception. During the current study, multiple tools were used to facilitate and record constant comparison during data analysis. These included memo-writing and diagramming throughout all three stages of coding.

4.8.3 Coding practices

As described by Walker and Myrick (2006), coding requires that data are broken down, each piece of data is compared with the others, and then the data is placed into categories based on apparent fit. Data relating to similar incidents are placed in the same category, while new incidents may lead to the creation of new categories. As Walter and Myrick explain, “coding is an iterative, inductive, yet reductive process that organizes data, from which the researcher can then construct themes, essences, descriptions, and theories” (p.549).

Within Corbin and Strauss’ approach to grounded theory, there are three levels of coding: open, axial and selective. While described separately here, these coding practices

are both iterative and recursive (Chen & Boore, 2009); this back-and-forth between levels of coding enables concepts and categories to be developed that are firmly grounded in the data, but that become increasingly abstracted from that data, moving beyond qualitative description, toward theory generation.

Open coding

According to Corbin and Strauss (1990), open coding is an analytical and interpretive process. They argue that “fracturing the data forces examination of preconceived notions and ideas by judging these against the data themselves” (Corbin & Strauss, 1990, p.423). As described by Birks and Mills (2011), this is achieved as the researcher identifies key words or phrases and then attach a conceptual label.

In the current study, a line-by-line approach was used to undertake open coding. The student researcher considered each line or phrase from the transcript and applied one or more conceptual labels. These labels were often low-level concepts and were largely descriptive at the beginning of the project. As new data were collected, the student researcher engaged in constant comparison, holding each new piece of data against existing codes to find both similarities and points of difference. As a result of this constant comparative analysis, some open codes were able to be condensed or combined, while others failed to reappear in the data and were thus discarded.

Axial coding

During axial coding, Corbin and Strauss (1990) explain that “categories are related to their subcategories, and these relationships are tested against the data” (p.423). Axial coding allows the researcher to combine and condense open codes into categories with

more abstract, conceptual labels, to fill out each category, and to start describing the relationships between concepts, subcategories, and categories. The aim of axial of coding is to ensure that each category is well developed in terms of its properties and dimensions (Corbin & Strauss, 1990).

For example, in the current study, multiple open codes were generated around the parent's access to their baby throughout their admission to the neonatal unit. These open codes were collected under the conceptual label "contact". The category "contact" was then explored regarding its properties (for example contact included physical contact such as touch or holding, as well as spending time with the baby alone or with family). The dimensions of the category "contact" were also investigated. Some families experienced "restricted" contact, meaning they were not able to be with their baby when they wished to be, while others experienced "facilitated" contact, in which parents were actively encouraged and supported to be with their baby. Having contact with the baby was a condition for "being a parent", while the type and degree of contact that parents had with their baby, before and after death, had a significant influence on their experience of memory-making.

Selective coding

During selective coding "all categories are unified around a central 'core category' and categories that need further explication are filled-in with descriptive detail" (Corbin & Strauss, 1990, p.424). The aim of these coding procedures is the development of a theory that has explanatory power, and that may have applicability beyond the context under investigation. In the current study, the concept of 'Affirmed Parenthood', was identified as the unifying concept, or core category, which created a link between all of the other

categories and explained the significance of memory-making for parents who had experienced the death of their baby in the neonatal unit.

An example of the evolution of data analysis through this process of open, axial and selective coding is provided in Appendix F. In this example, open codes relating to the concept “contact” are provided, including relevant analytic memos; during axial coding these open codes were condensed to form a category (contact), and the properties and dimensions of the category were developed. Finally, the category was analysed in terms of its relationship to the core category of ‘Affirmed Parenthood’. The same process occurred to enable the development of each of the eventual categories and their subcategories, resulting in a theoretical framework that explains the psychosocial process of memory-making in neonatal end-of-life care.

Use of Qualitative Data Analysis software

Qualitative Data Analysis (QDA) software is increasingly used to support data management and analysis in qualitative research. Hutchison et al. (2010) argue that “qualitative data analysis software can be used to encourage good quality grounded theory research by facilitating many of the key processes and characteristics associated with this approach” (p.283). In particular, the authors claim that NVivo supports the iterative nature of grounded theory research and may help to improve transparency in the research process, ultimately enhancing the validity of grounded theory research (Hutchison et al., 2010). Henwood and Pidgeon (2003) also argue for the use of QDA software in managing large and complex data sets. The authors point out that despite concerns about the effect on software on the creativity of the grounded theorist, “it is still

the researcher who must provide the interpretative work that generates the label and who decides which segments of data to compare” (p.139).

In the current study, NVivo 11 (QRS International) was used to manage the large volume of open codes and facilitate the recognition of potential links between codes, concepts, and categories. The student researcher transcribed each interview verbatim, and, after removing identifying information, loaded the transcript into NVivo. A new node was created for each open code as open coding was conducted. As it became apparent that these nodes were conceptually linked, higher level nodes were created to act as tentative categories and nodes that appeared to relate to the same concept were condensed or combined. In particular, the ability to search for keywords and to readily move back and forth between new and existing data facilitated constant comparison and led to the identification of subtle connections that may have otherwise been lost.

Memo writing

Strauss and Corbin (1990) describe memo writing as a system for keeping track of “all the categories, properties, conceptual relationships, hypotheses” and “generative questions that evolve from the analytical process” (p.422). Jeon (2004) adds that “Writing memos helps the researcher become more analytical and reflective as well as helping to retain and elaborate thoughts and striking ideas, which in turn helps to develop theoretical codes” (p.253). Strauss and Corbin (1990) caution that if the researcher moves directly from coding to writing, there is a loss of conceptual detail that will result in a lack of integration and elaboration in the analysis itself.

In the current study, memos were recorded through all stages of the data collection and analysis cycle. Field notes were written immediately after each interview, with the student researcher recording observations about the participant and setting, and early questions about the data. Memos were also recorded in NVivo during each level of coding. For example, during open coding memos were attached to individual codes, exploring what these codes might mean and how they might relate to each other. During axial coding, memos were written that captured the development of categories with regard to properties and dimensions. Finally, during selective coding, memos were used to support the identification of the core category and to document the evolution of the explanatory model from its earliest conceptualisations to the substantive theory in its current form.

4.8.4 Theoretical saturation

Within a grounded theory study, the data collection and analysis cycle continues until theoretical saturation is achieved. According to Bowen (2009), saturation is achieved when data are gathered “to the point of diminishing returns when nothing new is being added” (p.140). However, Corbin and Strauss (2008) add that theoretical saturation also “denotes the development of categories in terms of their properties and dimensions, including variation, and if theory building, the delineating of relationships between concepts” (p.381). This distinction may be particularly useful in differentiating between superficial analysis of the data, in which saturation may appear to be achieved relatively quickly, and saturation of emergent categories that allows for the development of a meaningful and useful theory from the data.

During the current study, saturation of each of the three major categories was achieved after the first 12 interviews. The final four interviews revealed no new categories of data and yielded few unique open codes. Most importantly, the data collected from all 16 interviews was sufficient to enable each of the major categories to be well delineated in terms of properties and dimensions, and allowed for the relationships between concepts and categories to be well described.

4.8.5 Development of theory

According to Corbin and Strauss (2015), theory is distinct from qualitative description in that it supplies an explanatory framework for events and interactions. They explain that while description and theory building both start with the identification of concepts and the development of categories, theory requires that these categories be linked with one another, and that each category be linked with a more abstract concept that they describe as the 'core category'. This core category should capture the essence of the data and allow the integration of categories into a theory, which has explanatory power.

The concept that was identified as central to participant concerns in the current study was 'Affirmed Parenthood'. This higher order concept enabled integration of each of the other categories into a substantive theory that has salience for participants and for experts in the field, and that helps to explain the phenomenon of memory-making in neonatal end-of-life care. This substantive theory is presented in Chapter Nine.

4.9 EVALUATING RESEARCH RIGOUR

The requirements for establishing rigour in grounded theory research differ from the traditional focus on reliability, replicability and validity seen in quantitative research (Maher, Hadfield, Hutchings & de Eyto, 2018). Furthermore, demonstrating rigour in grounded theory may be somewhat different from demonstrating rigour in other forms of qualitative research. In grounded theory, the primary means of establishing rigour is to ensure stringent application of the steps and processes inherent in the selected grounded theory approach. Corbin and Strauss (2015) draw on the work of Pryor (2009) to explore how elements of the grounded theory approach, such as prolonged engagement in the field, microanalysis of the data, and constant comparative analysis at each stage of data analysis, help to ensure that the resulting theory is credible. Corbin and Strauss (2015) add that researchers must provide adequate evidence on how data were collected and how analysis was performed to enable readers to understand how the researcher developed the theory from this data. For this reason, a detailed exploration of each category and subcategory, drawing on *in vivo* quotes from participants, is presented across three chapters in this thesis, while the procedures for data collection and analysis have been described in-depth.

In addition to the structures inherent in grounded theory research, Cooney (2011) provides criteria for establishing rigour in studies using Corbin and Strauss's approach to grounded theory. She argues that rigour can be improved through "cross-checking emerging concepts against participants' meanings, asking experts if the theory 'fit' their experiences, and recording detailed memos outlining all analytical and sampling decisions" (p.17). These criteria are less detailed but potentially compatible with those

proposed by Chiovitti and Piran. Chiovitti and Piran (2003) describe multiple methods for enhancing rigour in a grounded theory study, including letting the participant guide the research, comparing emergent theory against each new participants' experience of the phenomenon and using invivo quotes and words from the participants in the developing theory. The authors also recommend documenting the decisions made around participant selection, and comparing each category of the proposed theory with the existing literature on the topic.

In the current study, the research questions were left deliberately broad, and interview guides were adapted to focus on the primary concerns of participants as they emerged from each interview, ensuring that this inquiry was guided by bereaved parents. This constant evolution of the interview guide also allowed emerging concepts to be checked with new participants. The results of the study are presented using direct quotes from participants to illustrate the categories and subcategories that comprise the proposed substantive theory. The thought processes and sampling decisions of the researcher were captured in memos and diagrams from the beginning of the research process. Finally, the discussion chapter demonstrates the relationship between each of the categories and the extant literature. The most significant of these processes, checking emerging concepts with participants, checking the fit of the theory with experts in the clinical setting, and memo-writing, are explored in more detail below.

4.9.1 Establishing credibility and evaluating 'fit'

Cooney (2011) claims that within Straussian grounded theory studies, credibility:

is evidenced by changes during the grounded theory study that show that the

methodology was applied correctly: for example, changes in the questions asked

as data collection proceeds, evidence of ‘checking’ of emerging categories with participants and earlier data and the appropriate use of theoretical sampling.
(p.19)

In the current study, the questions asked at each interview were revised based on the emergent categories and subcategories. For example, as parenting emerged as a significant theme in the initial interviews, specific prompts were added to subsequent interview guides to check this concept against each new participant’s experience. This enabled the development of categories that were well defined in terms of properties and dimensions, ultimately improving the rigour and the clinical ‘fit’ of the research.

In this study, the decision was made not to use member-checking in its traditional form. Member-checking can take multiple forms, from returning transcripts to participants to confirm accuracy, through to conducting further interviews or focus groups with participants to enable them to confirm, modify or verify their own contribution to the data, and potentially comment on the emerging analysis (Birt, Scott, Cavers, Campbell & Walter, 2016). Cooney (2011) argues such an approach to member checking is less useful in the context of grounded theory, where the aim is to generate an abstracted *explanation* of the psychological or social processes occurring across participants and incidents, rather than to *describe* the lived experience of the individual. Instead, both Cooney (2011) and Cutcliffe (2005) recommend obtaining expert feedback and advice, rather than attempting to check the emergent concepts and categories with past participants of the study. Both authors argue that the most useful way of determining credibility is to evaluate the extent to which experts in the field view the theory as having ‘fit’ with the situation.

Rather than using traditional member checking, expert opinion regarding the emerging theory was sought. Both the initial themes and the final theoretical model were presented at national and international conferences. In particular, significant feedback was provided on the emergent theory by experts in the field during a poster presentation at an international conference for the Perinatal Society of Australia and New Zealand in March 2018. A range of senior clinicians provided informal feedback, including neonatal nurse practitioners, registered midwives, registered nurses, social workers and neonatologists. In addition to their clinical expertise, each of these practitioners was also involved in conducting research in the field of neonatology. These clinicians provided positive feedback regarding the fit of the emerging theory with their own experiences in practice, and the utility of the model in supporting neonatal bereavement care.

4.9.2 Memo writing, diagrams and the audit trail

Throughout this research project, memos were kept, recording both the decision-making process during coding and during theoretical sampling decisions. The majority of memos were in written form and captured insights into the meaning inherent in the data, decisions about open coding, the properties and dimensions of nascent categories, and the potential links between categories and their subcategories, or categories and the core category. These relationships were also at times captured in diagrams. As described by de Silva Barreto, Garcia-Vivar and Silva Marcon (2018), diagrams are a visual form of memo writing that help to represent relationships and facilitate mapping of categories and subcategories in grounded theory research. These memos (both written and diagrammatic) formed the basis for an audit trail for this study.

In grounded theory studies, an audit trail acts as a systematic record of both the process of data collection and analysis, and the analytic process underlying theory development. In this context, an audit trail is created to explain the processes, “and document the decisions in moving from raw material to final interpretation of the data so that the process of theory development is both visible and verifiable” (Bowen, 2009, p. 307). Bowen argues that maintaining an audit trail enables the concepts, categories and final theory to be demonstrated to have “emerged directly from the data, thereby confirming the research findings and grounding them in the evidence” (p.307). By recording memos as decisions were made about data collection, and insights were gained about the meaning of that data, an audit trail was created that serves to enhance the rigour of this study.

4.10 CONCLUSION

Grounded theory was selected as an appropriate methodology for this study for several reasons. Firstly, grounded theory research enables the development of a contextually driven substantive theory that can be used to guide practice. Given the wide variability in memory-making activities, and the lack of evidence to support best practice, the ability to generate theory that has immediate fit and relevance to the area of practice was identified as a significant benefit of the method. Secondly, grounded theory research is ideally suited to the study of social and psychosocial phenomena where little evidence already exists. As little evidence currently exists about memory-making in the context of neonatal loss, grounded theory is a suitable methodology to underpin this study. Finally, the approach to grounded theory described by Corbin and Strauss (2015) fits well my own philosophical position as a clinician and researcher, while the underlying assumptions are

well suited to exploring a complex social and psychosocial process that is fraught with different meanings.

While there are significant differences in the approaches to grounded theory espoused by Glaser, Corbin and Strauss, and more recently by Charmaz, Bryant and others, grounded theory studies are distinguishable from other forms of qualitative inquiry by several key features. In particular, theoretical sensitivity, theoretical sampling, constant comparative analysis, coding procedures and memo writing are hallmarks of grounded theory research. These canons of grounded theory were used as the basis of the current study, ensuring the development of a robust substantive theory that has relevance and utility in the context of end-of-life care in Australian neonatal units. In the following chapters, the three key themes that emerged from the research will be described, while the substantive theory, Affirmed Parenthood, is presented in Chapter Nine.

Chapter 5: **Finding 1: Being a Parent**

5.1 INTRODUCTION

The purpose of this grounded theory study was to explore the significance and impact of memory-making practices for parents experiencing the loss of an infant in the neonatal unit. Three key psychosocial processes recurred throughout the data in relation to memory-making for this group of bereaved parents. This chapter will explore the first of these processes, “Being a parent”. “Being a parent” emerged as a central concern for participants, and was comprised of three subcategories: contact, engagement, and caregiving.

5.2 CONTACT

The sub-category “contact” captured parents’ ability to spend time with their baby during their stay in the neonatal unit, as well as physical contact, such as touching and holding their baby. Parents described multiple barriers that acted to restrict contact, as well as describing incidents or circumstances that facilitated contact with their baby. Having contact with the baby was described by parents as being valuable in its own right. However, contact was also a necessary condition for participants to engage in other elements of “being a parent”, including engaging with the baby and providing care.

5.2.1 Spending time with the baby

Spending time with their baby was described by all participants as an important aspect of their experience and formed the basis for all other memory-making activities. Parents placed significant value on spending time with their baby while they were alive. For example, one father reflects on the time that he and his wife spent holding their baby the morning that he died:

P9: So (wife) and I had about an hour and a half, or more, with just him and I. And that was a really precious time, which we didn't realise at the time, but it gave us time to say goodbye.

Several parents similarly reflected on the importance of uninterrupted time with their baby, either just as a couple, or including their other children. One mother describes being moved into a private room after the decision to withdraw life sustaining treatment had been made:

P4: we had him to ourselves. So medical interventions.... They really did leave us alone to some extent, which was really nice. And allowed us to just be in a room with him by ourselves, kind of away from everybody else.

Another mother recalls spending time with her baby, husband and daughters:

P6: So we went in there and had some family time with the girls. And sang him some songs, and did all that sort of stuff.

Having uninterrupted time with the baby as a family, while the baby was alive, was seen as significant by these parents.

Parents of twins spoke specifically about the value of spending time with both of their babies together and were grateful when this was facilitated:

P15: when she got moved to SCBU, and (baby) was still in NICU, just trying to visit the two was really hard. So they ended up letting us take (sibling) out of SCBU and bring her into NICU, so that we could sit with the two of them together.

Another mother recalls having her twin sons in the same bed briefly:

P7: So that was amazing. You know, just that connection, and that opportunity that they allowed us to do that. You know, I think they knew how important that was. And we were really lucky. Their cribs were side by side, so we always kept them close.

Having their babies together allowed these parents to spend time with both babies and allowed them time as a family while both babies were still living.

Each of the parents who participated in this study also had some form of contact with their baby after the baby had died. Most parents described spending the hours immediately after their baby's death holding them, providing physical care, or being together as a family. For many parents, this time together after their baby's death provided an opportunity to say goodbye. For example, one couple describes being taken to a bereavement room while their baby was disconnected from medical equipment, and the baby being brought to them:

P11: And they brought him down once they had cleaned him up and everything. So we were able to just sit with him for one last time.

Being able to spend uninterrupted time with their baby was perceived as helpful by these parents.

For some parents, this time with their baby was both valuable and emotionally difficult:

P5: So yeah, we got some time in the bed with him (inaudible) but it was really really hard. I mean I'm glad I had that time. I am sure a lot of other people would stay, but at the time, it was just a few hours.

However, having uninterrupted time with the baby after their death was described as valuable by most parents. For example, when asked what messages she would give staff about caring for bereaved parents, one mother said:

P3: I think for staff to know that the time that you give somebody with their baby is so... so important.

Similarly, a mother of twins explains the significance that time with her babies held for her:

P1: I got to feel like they were mine, rather than just something that happened. Rather than just this pregnancy that never did anything. They were real people. And they even had personalities and um... yeah.... They were real. It was very real thing that I did. And yeah, it made them a real part of our lives, and not just this bad thing that happened in hospital one time.

For this mother, the opportunity to spend time with her babies allowed her to develop a sense of them as 'real' individuals and acted to validate their existence.

Spending time with the baby was also facilitated when staff provided care in an unobtrusive way.

P4: it was really nice. There were still things that they had to do, coming in and checking on him and pain relief and things, but it was minimal. They were really discreet when they did have to be there.

Similarly, another mother explains:

P15: We knew that the nurses were there, they would make themselves known outside the door but they didn't intrude in any way. But to have that time and also the space. To have the space was really good.

She adds: And there was no pressure. The doctor stuck his head in, just to check on him every ten minutes, just to make sure... to work out whether he was alive or dead basically. But we were then told we could have the room for as long as we wanted.

For these parents, the capacity to spend time with their baby in the hospital setting without feeling rushed or being interrupted by staff was viewed as being valuable.

The majority of parents felt they had been given ample time with their child after they had died, and this was seen as an expression of caring. For example, one couple explains:

P10: they never rushed us.

P11: that was the nice thing. It wasn't like they were "come on, we've got to go home sometime today" sort of thing. It's like they really showed such a caring nature that I was very impressed by.

Another mother reflects on the importance of having unlimited time with her baby:

P3: That was very kind and generous on their part. In allowing us to keep grieving, and not putting a timeframe and sort of saying "you need to finish this now." I think it was lovely that they gave us the time that we needed.

Spending time with the baby was critical to parents' experience of memory-making, and this was enhanced when parents perceived that they were not being rushed.

However, this was not experienced by all parents. Another mother recalls feeling rushed when staff kept intruding:

P14: But I must admit, I sort of felt a bit of... they kept coming into the room, you know "do you need more time" ... yes please. And I think the third time they came in my husband said "come on let's go". So yeah, I do remember feeling that pressure. It was 6-o'clock in the morning. They probably wanted to go home at 7.

These parents wanted to spend time with their baby; however, constant intrusions by staff made them uncomfortable, potentially compromising their contact with their baby.

In addition to spending time with the baby immediately after death, most parents were offered the opportunity to visit their baby in the mortuary, or to have their baby brought back up to their ward, should they wish to see them again.

P3: And they always said "if you would like us to bring her back we can." She adds: we were just lucky that we weren't rushed at all and we were given that offer to see our baby again.

While parents seemed to appreciate the option to see their child again after being transferred to the mortuary, most declined, feeling it would be too distressing to see their baby after having said goodbye. For example, one couple explains:

P15: when we handed him back we got told that if we wanted, they would take him down to the morgue in the hospital, but that if we wanted to see him afterwards, they could bring him up any time. But we kind of... once we'd said goodbye that was it.

P16: I certainly would have struggled to see him for sure.

P15: I was ready to acknowledge that he was in the morgue, I wouldn't have been able to bring him back.

For some parents, the baby's transfer to the mortuary represented saying goodbye. In this context, the offer to have the baby's body returned to the ward was overwhelming and was often refused.

Another mother describes her decision not to see her baby after he had been transferred to the morgue:

P2: I know after he passed away, they did come in and give us the option for them to bring him up to see us. And we did decline that. At the time I just felt a bit overwhelmed. And I guess now I feel like maybe I should, but at the time it was the right decision. And I am grateful that they offered.

While these parents declined the offer to see their baby after transfer to the mortuary, it is apparent that they were not offended that the offer had been made.

Interestingly, two parents identified that their decision not to see their baby after they had been transferred to the mortuary was based on a need to retain their image of the baby as they were when they were alive:

P12: they did offer for us to see her in the morgue, but we chose not to. Because, I don't know, we'd seen her alive, I didn't... we didn't know what was normal, either, but I didn't want to see her not alive, I suppose.

One father explains this decision in more detail:

P8: And we were very conscious that we did not want our beautiful beautiful images and memories in our brain to be changed. There are a couple of times where we did look at her, at her face after her colour had changed, and they made us feel very uncomfortable. So I think the vast, vast majority of our memories are of (baby), still nice and warm and a beautiful pink colour. And I am very happy that we actively chose to not allow the memories of how she looked at the very very end almost override earlier.

For these parents, the decision to limit contact with their baby after the changes associated with death had occurred allowed them to preserve memories of their living child.

While most parents declined the offer to see their baby again after they had been transferred to the mortuary, two mothers did accept this offer. For one mother, this involved having the baby brought to her hospital room for brief periods over the course of several days:

P12: We had a few family members in (town) when he was dying, and when he actually passed away, but then we had other family, like my mum and other family members that came to the hospital hours after he had died. And they brought him in to the room. So for about three days after (baby) died, they would bring him in to the room from the morgue. And we would nurse him. And my family members would get to see him.

For this mother, the opportunity to spend time with her baby after his death, and to hold him as she would a living baby, also allowed her to introduce him to family members.

Another mother explained that while she was in the neonatal unit visiting her surviving twin, the nursing staff would ensure she had access to the baby she had lost, without having to go down to the mortuary:

P7: If we'd called to say we were coming in, they would go and get (baby) out of the morgue, and often one of them was warming him up for us when we came in, they were cuddling him.

She explained that the nurses would set up an open cot in the room so that she and her husband could spend time with their living child as well as the child they had lost. This was seen as a gesture of caring and respect from the staff and was appreciated by this mother.

Conversely, one mother described her regret at not being offered the opportunity to see her twin boys again:

P1: If one of the nurses had have said to me, "if you want me to go and get them, I will get them for you", I would have gone (gasps) "yes, yes!", but I didn't know I

could do that. I didn't know anything – I was so stupid, I was so naive. And didn't know.... But it's such a big thing. She adds: Yeah, that was my biggest regret. I wanted to hold them and have a sleep with them. And just a myriad of things.

While most parents chose not to see their babies after they had been transferred to the mortuary, the offer to do so was not associated with distress. On the other hand, parents who were not offered the option of spending time with their baby after transfer to the mortuary expressed regret at this missed opportunity.

Taking the baby outside

While less common, a few parents spoke of spending time with their baby in the hospital grounds. For example, one couple recalls:

P10: I think I even took him outside.

P11: yeah, you took him outside, holding him. And yeah... it was nice to be able to do that with him.

Another father reflects:

P17: to get him outside was a mission. I think we had around six nurses pushing the bed with the ventilator, we had to have the doctor there, we obviously had all the family waiting out in the courtyard and we just wheeled him out, and we captured that, as the sun was coming out over the building, it started at his feet and worked its way up to his head. So we couldn't have planned that!

Conversely, for a few parents, not being able to have their baby outside was a regret:

P13: I would have liked her to go outside. She adds: Yeah it would have been nice.

I would have felt comforted if she had had that opportunity I suppose.

While not all families would wish to take their baby outside of the NICU environment, having the option to do so was appreciated by these parents, helping them to form positive memories of spending time with their child in a “normal” environment outside of the NICU.

Taking the baby home

In addition to spending time with the baby in hospital, two parents described being offered the opportunity to take their baby’s body home. One mother, whose baby had been home for a number of days before being readmitted to the neonatal unit chose not to take her baby home after he had died:

P5: they even offered us to take him home. But we chose not to. That’s not something I wanted to do.

For another mother, the option to take her son home overnight was appreciated:

P7: then she allowed us to take him home. So she filled out all the paperwork, gave me a letter, and we were able to take him home that night.

While not all parents who were offered the option of taking their baby home chose to do so, being offered this choice was viewed as helpful by bereaved parents.

Conversely, some parents who were not offered the option of taking their baby home expressed regret. For example, one mother who experienced her loss 17 years previously reflects that she would have deeply appreciated the opportunity to bring her baby home:

P14: Just the experience of being a family for a day instead of 6 hours. Just the two of us being with him. I know they do offer those sorts of things these days, but...

Despite the loss having occurred so long ago, for this mother, the missed opportunity to bring her baby home still caused feelings of regret. Another mother who had experienced a more recent loss explains that she didn't know that her sons could have spent a night at home prior to their funeral:

P1: I wanted the funeral directors to bring them to the house. So that they could be in our home. And I now know that that could have happened, it was a very simple thing. They had the facilities to do that, and they could have spent the night, and the whole thing.

Being offered the opportunity to spend time with their child after death was appreciated by families even when these offers were declined, while not being offered such options caused considerable regret, even years after the loss.

Spending time with the baby was a significant aspect of parents' experience of end-of-life care in the neonatal unit. Parents wanted opportunities to spend time with their baby while they were alive, but also appreciated opportunities to be with their baby in the hours after death. While feelings about seeing the baby after their transfer to the mortuary were mixed, parents appreciated offers to have the baby brought to them while

in hospital, or to take the baby home. Spending time with the baby was fundamental to forming a bond with them and was a condition for all other activities within the category “being a parent”.

5.2.2 Touching the baby and holding the baby

When asked about their most significant experiences with their baby in the neonatal unit, each of the parents in this study identified physically touching or holding their baby as critical. One mother describes being taken into NICU while the staff were attempting to stabilise her baby:

P3: I got to touch her. (Name), my partner, he got to stand there, he got to touch her.

While most physical contact was regarded positively, holding the baby was especially significant for these parents. For example, one mother recalls:

P12: (the nurse) took him out, and I nursed him. Thank god. And I nursed him for... probably about three hours. She adds: Holding him was huge. Huge.

Another father explains:

P8: We had many cuddles, up on our chests, in our arms. We cuddled heaps. He adds: It was mainly just talking with her, and cuddles. Physical touch was very important.

As with spending time with the baby, parents particularly valued opportunities to touch and hold their baby while they were alive. For example, when one mother was asked to

describe the aspect of care that had the most significant impact on her experience of loss, she stated:

P5: I would say it's mostly just been being able to hold him. Especially before... while he was still alive.

Similarly, another mother explains:

P12: So yeah I think if there is a baby, and the baby is going to die, I think nursing them as a mother, nursing that child is so important. It's so, so important.

For these mothers, the opportunity to hold their living baby was an invaluable experience and a significant aspect of memory-making.

While holding the baby was important to parents, it was also described as stressful at times, particularly when the baby was being ventilated or was unstable:

P14: They really really encouraged us to get him out and hold him. And that I value a lot. Because at the time I didn't want to, because it stressed him out so much. But looking back I wish we had have had more experiences holding him and cuddling him. So that was really good.

For this mother, encouragement from staff was needed to overcome her fear of causing her baby discomfort or distress by handling him. Despite her initial reluctance, this mother reflected on the importance of experiencing physical contact with her baby.

Similarly, another father explained the stress associated with holding his daughter:

P8: I found it very stressful whenever they were transferring her though. Because they needed to undo lots of plugs and stuff starts beeping, and they try and re-plug

everything back in when she's on you and so it wasn't a relaxing time until she was there and stable. And then sometimes she'd overheat, and sometimes she'd get too cold when she's on you, and they would need to quickly get her back off and cables fall out and you're like "agggghhhrrr!". But it was worth it. Yeah.

Despite the effort and anxiety involved in holding their babies, these parents still regarded this contact with their child as being significant.

Finally, one father spoke with gratitude about the staff who enabled him and his wife to hold both of their twins at the same time, despite one being full ventilated and the other being cared for in a separate unit:

P16: They went out of their way to try to do things. Like we got to cuddle the two together. That I thought was really good. Having the two kids together and us all together was really brilliant. And the midwives there went out of their way to do that.

Touching and holding their children while they were alive was an important aspect of "Being a Parent" and helped participants to form memories with their baby that were non-clinical in nature.

All of the parents in this study were present at the time that their baby died, and the majority describe the baby being held as they died, either by themselves or by their partners. For most parents, this occurred as part of planned extubation.

P2: When we had to turn off his care... we were allowed to hold him until he passed away, and all of our family were allowed to be there.

P5: As he was dying, when they were going to turn off the machines, they gave us, like a couch and they passed him to me to hold. To me and my husband.

While recounting this experience was often emotional for parents, several also expressed being grateful to be able to hold their children as they died.

P2: he was in my arms while they were removing everything, so it made it a little bit... made the process a little bit easier I guess.

For another couple, the death of their baby occurred despite full treatment; however, efforts were made to enable them to hold their son as he died:

P15: when they saw us they came and got us because he'd just started to deteriorate. And so what they ended up doing... they knew that he wasn't going to make it, it was quite bad. So they ended up taking him off all of his tubes and took him out of the incubator, and they gave us a private room across the hallway. So we were able to hold him as he died. So that was just amazing. That was a really invaluable experience. He was 99% gone before they got him out, but we were there with him.

Finally, parents who experienced the death of either one or both twins described the importance of being able to hold both babies while treatment was withdrawn:

P1: I just asked if they could.... If I could hold them while they passed. And um (pauses). They um, laid them on my chest (tearful). And um... removed the tubes. And I got to hold them while they passed. And um... yeah, I got to hold them for quite a while. I think if that hadn't have happened, it would have been a massive

regret. So, yeah, that was really important. Yeah. I was lucky enough to do that, so that was good.

P7: we were able to cuddle both the boys as (baby) passed.

Despite the heart wrenching nature of this experience, parents described it as being deeply important to them to hold their child during their final moments. Physical contact, such as touching or holding, was a significant experience for participants and was an aspect of the parenting role that was valued.

5.2.3 Restricted Contact

While being present and having physical contact with the baby was described as meaningful by all participants, there were numerous barriers that impacted on the contact that parents were able to have with their baby. Being physically separated when the baby was transferred into NICU or between hospitals was common and was distressing for parents. Mothers who were unwell at the time of their baby's birth also described having restricted contact throughout their babies' NICU stay. Finally, medical technology and a focus on avoiding deterioration also impacted on the physical contact that parents were able to have with their babies.

Being Separated

Many of the parents in this study experienced periods of separation from their baby. Most commonly, the baby was delivered via caesarean section and taken directly from the operating theatre to NICU:

P2: I had to have a classical caesarean, so they had to cut up and down, rather than across. And he got taken straight to the NICU. And so the hospital staff took photos of when he was born and gave them to me as I wasn't able to see him straight away. And it wasn't until about four hours after he was born that I was actually allowed to go down and see him

P15: We didn't get to see him, he was taken straight away. And then we are approached by the doctors to say that things weren't well. So he got whisked straight to NICU.

Separation also occurred when infants were transferred between hospitals, often for more complex care. For example, one mother reflects on her baby's transfer:

P10: I just gave birth to him, they'd just sewed me up, I got five minutes to see him, and he got taken to a different hospital and I was in a ward filled with mothers and babies crying. So when they are in NICU, you are not with them. It was like that for me because I had a c-section. I don't know what it's like if you have a natural birth. But you sort of feel.... What just happened? You feel really empty.

Another baby was transferred to a tertiary centre after immediate stabilisation. However, a bed wasn't available for his mother in the same hospital until 36 hours later:

P6: The NETS team turned up and it was 6 hours to stabilise him, put him on the plane and get him to (city). My husband went down to (city) with him. I was still at (regional hospital). He left at about 3 o'clock in the morning my husband said. And I was just there until the Sunday morning when they could get me a bed.

Finally, one mother describes her separation from her baby in more detail:

P2: I asked them if I could see him when he was born, and they said no. and he was taken straight to the NICU. And working in the medical profession, I understand the need to get him there as soon as possible. But when they took me to my room, and I was asking when I could see him, they were saying “no, not yet”, “no, not yet” but they wouldn’t give me a time. And it wasn’t until I’d been asking for about four hours that they finally organised for me to go down. And when I got there, there wasn’t really any reason for me not to be able to go down. They said they were happy for me to be there, as long as I followed the precautions and washed my hands and everything. So that wasn’t until about midday that I got to see him. And then they next let me down at 7o’clock at night when it was an end-of-life decision. So I wasn’t very impressed with the limited amount of time they let me spend with him.

The physical condition of these babies often necessitated transfer to a specialist unit or even to a different hospital. For these parents, physical separation from their baby immediately after birth was experienced as distressing, even when it was understood to be necessary. This separation, whether hours or days in duration, restricted contact and therefore impacted on memory-making for these families.

In addition to necessitating transfer and therefore causing separation, the medical instability of these infants often impacted on the amount of physical contact that parents had. Parents frequently described limiting contact with their baby when they perceived the contact as a potential trigger for deterioration:

P6: It's that feeling of helplessness and hopelessness when you're standing there. You know, every time you touch him, his blood pressure would either drop through his boots, or go through the roof.

P18: We didn't have a lot of time with him being out of the crib or anything because he was so little. And with his breathing and all of that's sort of thing. Literally every minute there was some little change. So didn't have very much time with him. We could stand at his crib which I did a lot and touch him gently, but we wouldn't take him out.

P10: Because of the situation he was in, we weren't able to hold him until the day he was taken off life support. So it was very hard, because we weren't able to have that form of contact until the last moment.

For another parent, physical contact had to be carefully orchestrated to avoid causing harm:

P18: something as easy as changing a nappy on him took a couple of people. When we used to sponge bath him, or use a washer to give him a wipe-over, we would have one nurse supporting his head, neck and one shoulder, another one coming from the other side under the other shoulder and his bum, and we would do some cleaning while they did that. So we had at least a three or four person job, just to give him a bit of a wipe over. He adds:

I think the hardest thing for us was the fact that we couldn't just pick him up and hold him. For me to hold him, it took... I couldn't even tell you how long it took for

us to organise for me to hold him. But it was still on a pillow. So there was no skin-to-skin until those final couple of days.

Concerns for their child's welfare, and the stressful nature of handling their baby, restricted the contact that these parents had with their child, impacting on their capacity to parent their child, and therefore reduced their opportunities for memory-making.

Mother's medical condition

In several instances, the mother's medical condition also acted to restrict contact. For example, one mother recounts being seriously unwell during the 24 hours that her babies were in NICU:

P1: I'd had a Caesar and hadn't reacted well to any of the drugs that they'd given me, and I hadn't reacted well to any of the pain medicine, so I was very wheelchair bound and had... I felt like I had a thousand pipes coming out of me. I only got up there once. And I couldn't actually hold them while they were ... because they were so small. And I couldn't actually touch them, because I couldn't actually reach my hand up to get in, because I couldn't get out of the wheelchair.

For this mother a combination of the medical technology being used to keep her babies alive and her own limited mobility prevented her from having physical contact with them.

Another mother describes being in the intensive care unit (ICU) as a result of the same condition that led to her baby's preterm delivery.

P13: she was on life support for four or five days, five days I guess. And at that time I was still in ICU and they brought her down to me (tearful), twice I think.

She adds later adds:

I remember wanting to put her on my skin. (crying) I would have liked that to have been offered. Because I remember wanting to do it, and I remember pulling at the gown, but I couldn't say it, I couldn't get it into words. I don't know which stage this was, maybe I wasn't even really communicating properly. But I remember thinking I just wanted her on my skin. I would have really liked that to happen.

Being physically unwell and unable to communicate clearly impacted significantly on this mother's experience of contact with her baby.

Parents in this study described a range of factors that restricted their contact with their babies. This most frequently occurred when babies were transferred, either from delivery to NICU, or from one hospital to another. The medical condition of both mother and child also acted to restrict contact at times. Mothers who experienced severe illness had difficulty in touching and holding their babies, while parents frequently reported limiting their physical contact with their baby for fear that it would result in harm or precipitate deterioration. Finally, technologies such as isolettes, cooling blankets and ventilatory support also impacted on contact, at times preventing parents from holding their babies or seeing them fully. Contact was a precondition for other parenting activities. Therefore, these restrictions to contact had the potential to impact on memory-making more broadly.

5.2.4 Facilitated contact

While most participants experienced at least some restrictions to contact, several also described factors that facilitated contact. Having accommodation within the hospital or nearby was described as facilitating contact, as parents were more readily available throughout their baby's time in NICU. Parents also explained that a shift in the focus of care from keeping the baby stable, to providing comfort to the baby and family allowed them to have more contact with their baby.

Being nearby

Several parents commented that having accommodation in or near the hospital enabled them to spend more time with their baby:

P8: Staying in the same building was really good. So we could just pop down the corridor and just visit, for a bedtime story or... you know, we could go 24 hours a day.

P18: (hospital) has a hostel, so it's actually part of the hospital, so that's where parents stay. So we were literally down the hallway from him.

P4: I was in (hospital) and he was in NICU there. So we stayed in the same place thank god.

Open unit visiting policies and support from staff was also described as helping to facilitate contact by several parents:

P4: We could come and go as we pleased. So (husband) his dad was with him pretty much the whole time. And beyond that, we could come and go as we pleased

Staying close to the NICU and having open visiting hours was reassuring for parents and enhanced their contact with their baby.

Shifting focus from cure to comfort

As described earlier, medical technology and efforts to keep the baby stable acted to restrict contact for this group of parents. Conversely, parents described the removal of this equipment and a shift in the focus of care from active treatment to comfort care as enhancing their contact with their baby

P7: once they ceased treatment, he was really just handed to us like a normal baby.

P9: we actually took away all his tubes and stuff and we actually got to hold him for that last couple of hours

P18: It was only when we knew that it was really serious, and he was dying basically that we had him out of the crib and we could hold him. He was still wrapped up with all this stuff but yeah.

Another mother describes the shift in focus from curative to palliative as allowing her more time to hold her baby:

P6: that meant we got more cuddle time. Once they stopped, they were worried about his blood pressure and stuff. But I was like “can you disconnect his art line? I don’t care. What’s the problem?”

Finally, one father explains that the decision to limit care meant the removal of cooling blankets, allowing easier access and allowing more skin-to-skin contact:

P8: In the first 48 hours of her being there, she was being artificially cooled. So she had a cooling blanket and everything on her. Once they realised that her brain activity was not improving at all, there was no need to keep her body cooled, so at that point they... she was a lot more uncovered. And I guess having her more like a baby should be, kind of thing, a bit more... a lot of skin showing, just a nappy. I think that helped us feel more connected with her as well.

The shift from a curative focus to a comfort focus allowed many of these parents an opportunity to see, touch and hold their child without the restrictions imposed by medical equipment and without concerns about causing harm. These final hours were regarded as valuable by parents and contributed significantly to their memories of their baby.

5.2.5 Summary: Contact as an element of memory-making

Each of the parents in this study identified that contact with their baby was central to their experience of memory-making in neonatal end-of-life care. Spending time with the baby was considered important, especially when this occurred while the baby was alive. Touching and holding the baby was a significant event for every parent in this study and helped them form memories with their baby that were treasured. While factors such

as maternal illness, separation and the baby's own medical condition had the potential to restrict contact at times, most parents also described factors such as staying close to the hospital, open visiting policies and a shift from curative care to comfort care as facilitating contact with their baby. Having contact with the baby was also a condition for engaging with the baby, and for participating in caregiving activities.

5.3 ENGAGING

The second sub-category that emerged as central to "being a parent" was engaging. Parents in this study described a range of strategies for "engaging with the baby" that helped them to bond and to form memories that were highly valued. Parents in this study engaged with the baby by studying the baby and by talking or reading to the baby.

5.3.1 Studying the baby

Studying the baby captured parents' descriptions of their need to examine their newborn closely. For example, one mother explains:

P14: I wanted to see him. I wanted to see his toes and his fingers, because I hadn't really... as much as I had touched him, I hadn't really held him.

For another mother, the opportunity to see her son's face properly was described as important:

P6: So it was good, with nothing there, I could finally see his little face. Because I'd hardly seen his face or his mouth until they withdrew treatment because it was all covered in tubes. Yeah.

Another mother describes the significance of studying her twin boys while giving them a final wash:

P1: And I just got to touch them and study their feet and study their faces. And just soak them in, not forgetting one little detail. She adds: That was really amazing. And that was really important. I can still close my eyes and see their faces eight years later. So um, yeah, that was really important.

For these parents, time spent studying the details of their baby's appearance was valued as an important activity, but also allowed them to form enduring memories of their children.

5.3.2 Talking and reading to the baby

Several parents also described talking with their babies as a way of engaging with them. For example, when asked which memory-making activities helped he and his wife feel like parents, one father explained that he talked to his daughter about all of the things that he wanted to do with her:

P8: I made a bit of a wish-list, of all the things... (tearful)... that I would have wanted to do, or that I.... so I made a long list of... I'm a mathematician, so just telling her about certain things in life. So I had a big list and we chatted about everything. That was... saying all those things that you don't get to say later. He adds: for me making that list of everything that I would like to say to my daughter and would have done... you know, walk her down the aisle, I can't walk her down the aisle, but I can talk to her about it.

For this father, having an opportunity to tell his daughter about all the things he wished they could do together was a meaningful way to engage with his baby, as well as helping to establish a sense of parenthood.

Several parents also described reading to their baby as a way of engaging with them while in NICU.

P8: We read her books. My favourite kids' books.

One couple described the significance that reading as a form of engagement holds for them:

P16: One of the memories I have is sitting there, we had Winnie the Pooh books, and we would sit there and read to him. I reckon we spent ages reading through this book to him.

P15: Yeah, and in fact that was something that one of the midwives suggested. She could tell that we just didn't know what to do, and she said, "well, why don't you read to him?" and so that then became our thing. And that is a really important memory, because we bought these Winnie the Pooh... one of the original Winnie the Pooh books, and we read it the whole way through to him. And that ended up being our theme for him. So we now use a Pooh Bear as a symbol for (baby).

P16: What we found that was really good was to feel like you were doing something. To feel like you were interacting and doing something with your baby.

For this couple, time spent reading to their baby helped them form positive memories and provided enduring imagery that they were able to use to connect with their baby after his death.

Finally, the use of music and play were described by some parents as a way of engaging with their babies. For example, one mother explains:

P10: And they encouraged us to really do things with him. We had these little music videos on our phones. And he loved them, because I played them while he was inside my womb. And he was smiling away. And just thing like that that they encouraged us to do was really good. Because we remember that now. Like when we hear the songs and when we look at his things, and his photos and that. You can just sort of remember what actually happened at that point in time

Not only did music help this mother to interact in a meaningful way with her baby, but it also provided an important anchor for her memories of him.

5.3.3 Summary: Engaging as an element of memory-making

Parents in this study interacted with their babies by studying their features, and by engaging with them through talking, reading or singing. Parents typically described these interactions in positive terms. Time spent engaging with the baby provided a meaningful source of memories for this group of parents. Restrictions to contact had the capacity to limit engagement, while facilitated contact increased opportunities for parents to engage with their baby.

5.4 CAREGIVING

5.4.1 Bathing the baby

For the parents in this study, bathing the baby was a quintessential caregiving activity that helped them feel like a parent to their baby. Several parents described the act of bathing their baby as one of the most significant memories they have. For example, when asked why bathing was an important activity for him, one father explained:

P17: being able to get him into a bath and have a good wash and have bubbles on him and that, it's just the normal things that you do as parents.

Similarly, this parent recalls that the nurse providing her with an opportunity to give her baby a sponge bath which helped her to feel like a mother:

P7: we bathed him, it was just a sponge, but she was really good. She allowed me... you know, she helped me to do all that, but gave me that mothering. Because when your baby's being looked after by others all the time, you don't get much of that chance.

Acts of caregiving, such as bathing, helped some participants to feel like their baby's parent in a situation where many of the "normal" activities of parenting were not possible.

For another mother, bathing the baby with one of her daughters was a meaningful way to include her older child in the baby's care:

P6: then we gave him his bath. Our older daughter was desperate to bath him, because we'd been talking about it for 7 months. How excited she was going to be to bath the little baby when it came. So that was important for us, to give her the opportunity to do all that sort of stuff. And we bathed him, and she helped.

The ability to engage a sibling in an act of caregiving helped this mother to include her daughter in the process of saying goodbye to her baby, and was an important part of her memory-making experience.

Bathing the baby was a meaningful experience for a number of parents. However, there was also a degree of stress involved in this caregiving activity at times, as occurred with other forms of handling or holding the baby. In particular, one mother explains that while she wanted to bathe her son, this needed to be done after he had been removed from life support, creating uncertainty and anxiety about whether he might die during the process:

P4: we were able to bath him, which was good. But we had to wait until they'd removed everything. So we had a lot of... it was just that uncertainty, because obviously once they remove things you just don't know how long they will last. So the hospital, I guess they can't... they just don't know, so they can't really plan for that. But we were quite lucky that we did get to bath him while he was still alive.

However, when asked which activities helped her form memories with her baby, this mother stated:

P4: I'm really really glad we got to bath him.

Despite the uncertainty, this mother regarded her experience of bathing her baby as valuable aspect of memory-making.

Finally, one father explained that while bathing his daughter was not a critical experience for him, it was an important aspect of caregiving for his wife:

P8: but bathing for me wasn't particularly... it didn't really mean a great deal. It was important for my wife, but I think... there were so many tubes and things, that there wasn't the option of bathing while she was still with us. But as a final step, it was important to my wife, for sure. He adds: bathing was very important to my wife. She was keen for that at the very end. So after having removed the life support. As sort of a farewell process.

This emphasises the potential differences in needs and experiences between members of a couple, as well as highlighting the role of caregiving activities in helping some parents to say goodbye to their babies in a meaningful way.

Unfortunately, several of the parents in this study were not given an opportunity to bath their baby, and this was a source of regret for some:

P15: one of the things that would have been cool, and this is only in retrospect, bathing him... even though he was dead, just bathing him afterwards. Because he still had all the tapes from the sensors and stuff. Especially on his face, from the CPAP machine. So having had the opportunity to bathe him, even though he was dead, afterwards, I think I would have appreciated that. She adds: Giving us the option to bathe him and dress him would have been awesome. We didn't think of it at the time, but it wasn't offered.

While this mother was generally positive about the end-of-life care her baby received, she was also aware of this missed opportunity to care for her son. Similarly, one mother who was critically unwell during her baby's brief life expresses regret that she did not get to assist with bathing her daughter:

P12: I wish we had washed her. I mean I don't know if they made the call not to do that because I was in an ICU. I guess I feel like I missed the chance to mother her. (crying). So I guess I would have liked it if... maybe I couldn't. Maybe I was so unwell that I couldn't, and they didn't offer it because of that, or they didn't do that as a practice then. But I would have liked to have done something like that.

This highlights the significance of caregiving activities in helping participants step into their role as parents, and the impact that missed opportunities for caregiving have on parents' experience of loss.

For several parents, bathing was undertaken by nurses without their knowledge or permission, and this was experienced as distressing. One mother recalls being given photos of her baby's first bath that had occurred without her consent:

P2: in one of the photos they had bathed him. And I felt quite disappointed that I hadn't been given the option to do that. So it was quite distressing, I guess, to see his first bath, and they had taken lots and lots of photos of it. And I know they probably were just doing their job, but, it would have been really good. I would have liked to have been able to do that.

The same participant later explains:

P2: I think the only thing that I was really distressed about was looking through the photos and someone else is bathing him. And I was really upset that I didn't get asked if I'd like to help. Because I think that's one thing that I would have really liked to have done. Was to bath him and dress him.

Another mother recalls being handed her son after he had been bathed by nursing staff:

P14: And then they brought him in. And they'd done everything. They'd bathed him; they'd dressed him.

This mother later reflects:

P14: I would have liked to have bathed him and dressed him and been involved in that process. But as I said, we were just shoved in another room. Like as if it was easier for the staff to not see us.

This mother felt as though she had been excluded from her child's final care because this was easier for the healthcare staff, and expressed regret about this aspect of care some 17 years later.

Bathing was described as a valuable activity by the majority of parents, whether they were given an opportunity to engage in this aspect of caregiving or not. Bathing was described by participants as helping them feel like parents, and was also a source of positive memories after their child's death. Several parents also mentioned dressing their child as part of this caregiving experience.

5.4.2 Dressing the baby and choosing clothing

For one mother, changing her baby's clothing after he had died helped her come to terms with the reality of his death:

P10: I changed him. It was nice to do that, because he... I wasn't able to put clothes on him much while he had all the wires on him. So to be able to do that was nice. But I think it also helped me understand that he was dead, if that makes sense.

Her husband later reflects on the importance of being able to dress one's child:

P11: just gives them an opportunity to have a bit of dignity, I guess. I mean I know babies probably don't think along those lines, but as a parent seeing your kids with clothes on is A nice feeling.

For these parents, the act of caregiving involved in dressing the baby was important in itself, helping them to acknowledge the reality of their loss, while also acting to preserve their baby's dignity.

Being able to dress the baby in clothes that had been made, or purchased for them, was also important to some parents. One mother explains that her husband was directed to bring in clothes from home:

P13: the hospital must have told (husband) to bring some clothes in from home, and that mattered. None of them were the right size (smiles) and I think... we didn't have any girly clothes, so we must have just gone with gender neutral when we bought things. So we have got some clothes that she did wear, which we kept, which I am glad we did.

Another mother explains the importance of buying her son his own clothes:

P4: I wanted to buy him some clothes because what we left him in at the hospital is what we actually had him buried in, or cremated in. So it was important to me that I buy him some clothes.

Finally, one mother describes the outfit that the baby's grandmother had knitted for him, explaining:

P7: there were things my mum had made, and I wanted to use those

Where possible, parents responded favourably to being able to choose their child's clothes, whether these were purchased before or after the birth, or made specifically for the baby.

For most families, clothing was provided by the hospital, particularly for babies who were born extremely premature and were too small for typical newborn clothing. In some instances, staff were able to facilitate choice, despite needing to provide clothing that was appropriate for the baby's gestation and size:

P6: we didn't have anything. The ladies at the auxiliary make all the little different sized clothes, so they had a little pack there with a coupled of options to choose from in the 26-28 week size. She adds: The nurse brought out a couple of options for us to choose from, so that was nice. And then I sort of... she was really good, she was great. Because I didn't like the beanie in one of the packs, but I liked the beanie in the other pack, and I didn't like the booties (laughs). And she's like that's alright, we'll just swap them all around.

For this mother, being given a choice of suitable clothing was a small but important gesture.

For another parent, the care taken by staff to find matching outfits for her twin boys was appreciated:

P1: I don't know who they had been donated by, but they came in a pack with clothes and blankets and the whole thing. And yeah, one of the NICU nurses had got them so that they matched... I don't know how she did that out of the thousands of packets... I now know what happens. And she got them to match, so that was really good.

Similarly, another mother commented on the care taken to choose clothing that was appropriately sized and coordinated:

P3: And the little booties and the little hat and the little cardigan, and everything that was in the box was appropriate to her size. Which I think was lovely. It wasn't just randomly put in and mismatched. Everything matches. So I think that's probably an important thing, that when the midwives or the nurses give out the boxes, that they check that they're going to be the right size for that baby, or as close to it as possible.

While these parents were not given the opportunity to choose their babies' clothing, the care taken in selecting appropriate items was recognised and described as being important.

Alternatively, some parents were not given the opportunity to choose their child's clothing or to dress them. This was a source of regret for one mother:

P5: I know this is going to sound really... I probably would have wanted to dress him in what I wanted. The hospital had their own clothes, but I had my own clothes that I wanted him in. That probably sounds really superficial, but... yeah, when I think of it that way it was pretty important. I mean I know they changed him later for the funeral. But I think even at the time I really wanted him in the clothes that I had. But it wasn't something that was really.... Obviously it's something that's stuck in my mind for some reason.

Being able to choose their child's clothing, or to dress them in clothing that had been carefully selected, was important to the majority of participants. Conversely, being denied this opportunity resulted in regret at times. Selecting clothing and dressing their baby helped parents to assert their baby's identity and dignity as a person, and was a fundamental act of caregiving.

5.4.3 Changing the baby's nappy

In addition to bathing and dressing, simple acts of caregiving, such as changing nappies, stood out for some parents as important experiences. For example, one mother explained:

P15: Certainly, things like changing his nappy and being involved in his cares, they stood out more so than just holding him. You felt so helpless, so actually doing something was definitely a stronger memory. She added: Just changing his first nappy, that was... that is a very vivid memory

For some parents, changing nappies was one of the few elements of caregiving they felt able to participate in:

P7: I changed his nappy. And you know, I was able to ... at that point we were not able to dress him, but we were able to change his nappy, which I hadn't done yet because he was so fragile. I was allowed to touch him, but I wasn't allowed to handle him.

When asked what aspects of care had helped him feel like a father, one participant explained:

P8: nappy change. For sure. Each of us got to do that a couple of times. It got a bit tricky when they had catheters and stuff in, but....

Similarly, another couple reflected on the importance of small acts of caring such as changing nappies:

P10: so it was a bit hard, just for a first time mum, when you can't hold him or feed him or anything like that.

P11: even just a simple change of nappy or something like that

P10: yeah, changing nappies was really difficult for me, but they sort of took that into account, and they encouraged me to do things. I was expressing for him, and so I was able to put a bit of milk in his mouth when they cleaned it. I was able to clean his mouth. I was able to wipe him down and clean him. So I did a lot with him.

The mother of this child later explained:

P10: So just being able to do those sorts of things, it made that bond with him. That most people would have gotten anyway. Just being able to be closer to him, to touch him and to clean him, and to feel useful. Because most of the time we just sat there, watching him and holding his hands, and we couldn't do anything.

For parents who experienced restricted contact with their baby, these small interactions were invaluable in helping them to establish a sense of parenthood and to bond with their baby in a meaningful way. Simultaneously, small acts of caregiving also provided parents with a source of memories that were valued after their baby's death.

Finally, one parent explains that as well as providing important memories, acts of everyday caregiving gave her a way to relate to other parents:

P4: Even just to change his nappy, just to do those little things that are just normal. And you know, it's nice to be able to have those stories, just to relate to other people. So that's probably the number one thing that we took away from it. Was that the more normality we could have, just in those little... that little bit of time, so that as a family we've got some memories that aren't just of, you know, him being sick, or him being treated, or... all the machines...

Having shared experiences with other parents was viewed as helpful, while engaging in "normal" parenting activities provided a source of positive memories for this mother.

5.4.4 Summary: Caregiving as an element of memory-making

Seemingly small tasks such as bathing the child, dressing them, choosing their clothing or even changing a nappy were seen as valuable by parents. When they had opportunities to care for their baby, parents developed important memories of their baby that were not centred on their baby's illness or death. Simultaneously, caregiving allowed participants to gain a sense of identity as their baby's parents. Conversely, missed opportunities for caregiving were recalled with sadness and sometimes regret.

5.5 CONCLUSION

Participants in this study spoke in detail of the strategies and actions that were central to "being a parent". Having contact with the baby, whether by spending time with the baby, or holding and touching them, were significant concerns for these parents and participants were able to explain in detail some of the factors that inhibited or enhanced this contact. Contact with the baby was also an important pre-condition to other elements of parenting, including engaging with the baby and caregiving. Caregiving was especially important to parents, helping them to build positive memories with their baby while stepping into the parenting role.

Chapter 6: Finding 2: Creating Evidence

6.1 INTRODUCTION

In addition to “Being a Parent”, “Creating Evidence” emerged as a significant concern for parents in this study, and was a key psychosocial process underpinning memory-making in neonatal end-of-life care. Each of the parents described a range of artefacts and experiences that helped create evidence of their child’s brief life. Parents engaged in creating evidence through having photographs, collecting and creating mementos, and involving others.

6.2 HAVING PHOTOGRAPHS

All of the parents had photographs of their babies that were taken during their stay in the neonatal unit. Photographs were described by participants as being crucial elements of their memory-making experience. Most parents described taking photos themselves, while others had family members who took photos for them. For example, one mother stated:

P7: we took lots of photos actually, which was good.

Another mother recalled:

P14: we’ve got our photos. My dad had a really good camera, so he took lots of photos. He probably took more... and he’s taken some really good ones of him.

Having an opportunity to take photos of the baby, either before or after death, was considered valuable by these parents.

The majority of parents were also given photos that had been taken by members of staff:

P3: I think somebody in the theatre took photos of her when she was on her resuscitation trolley, and then (husband) took photos in the neonatal intensive care unit, where they were working with her. And I remember they took a photo because we are all in it.

Some families also described staff taking photos discreetly as a routine part of care:

P15: we didn't ask for it at the time, and they did it really unobtrusively. Like with the photos, we would be cuddling (baby), and we would look up and they would have a camera. And so we didn't even know that they were taking a photo.

When asked what aspects of her care in NICU had been most helpful, this mother added:

P15: even little things, like they used to, every time we got (baby) out of the incubator, they would take a photo. So they were just running around with the camera. And it didn't even occur to us at the time, but afterwards having those photos was just really invaluable.

Being encouraged or supported to take photographs, and having photos taken by members of the health care team was described as helpful by these parents in hindsight, even if taking photos was not a significant concern at the time of their loss.

The majority of parents also had photos taken by professional photographers. In the case of parents who experienced their loss prior to 2009, these were often taken by the hospital photographer. For example, one mother explained:

P1: the NICU social worker, she organised the medical photographer to take some photos. Which was great. And yeah, he was really good.

Another mother explained that she was initially reluctant to have the hospital photographer come in, feeling that they had already taken sufficient photos of the baby:

P7: she came to see us in the NICU, and she said, "I strongly recommend you have photos taken." And I said, oh, we've had lots of photos taken, it's ok. We've taken a lot of our own photos. And she said "I'd strongly recommend that you have professional photos taken. We can offer this service." So initially, I was like, oh... I didn't want to put people out, but she really gently pushed for it. And it was good. It was great. So we had professional photos.

Although this mother was concerned about wasting other people's time or resources, she was eventually grateful that she had those photos of her son.

Since 2010, the services of a not-for profit organisation called Heartfelt have become increasingly available to parents in Australia and New Zealand, meaning that most of the parents who experienced more recent losses had photos taken by a Heartfelt photographer. The photos taken by Heartfelt were universally described in positive terms:

P6: The Heartfelt people were incredible. It was only an hour out of our day and she took some beautiful photos of our whole family together and... yeah. They are very treasured photos.

Similarly, another mother described the photos taken by Heartfelt:

P4: those photos are really nice. And it's something that we do have out on display now.

In addition to appreciating the photos as evidence of their baby's existence, parents were also positive about their experience of having these photos taken. For example, one father explained:

P8: So yeah, we are really happy we got them in. I know one family that didn't get them in and I get the sense that they were very regretful that they didn't because I think that a professional photographer can do stuff that can't otherwise be done.

Another father identified that having a third party take the photos allowed him to be in the pictures with his wife and son:

P17: they said it would be nice to get some photos taken of us as a family. Because when we were taking photos, obviously whoever is taking the photo isn't in it.

Despite being initially hesitant about having professional photos taken, this service allowed this father to have photographs of all his family members.

In addition, the professionalism of the Heartfelt photographers was commented on by several parents:

P4: they didn't impose on us in being in the room. So it still gave us that time together as a family, without having a stranger in the room, kind of ... you know, at the worst moment of our lives.

P17: she didn't make us feel like we were posing. We didn't even realise she was there. She was in the background, but she captured so many different memories and suggested different things.

This sensitive and unobtrusive approach helped parents to feel comfortable with having pictures taken in an emotionally intense situation. While some parents expressed initial reluctance to have professional photos taken, all of the parents who had engaged with professional photographers expressed gratitude for this opportunity during the interview.

Conversely, parents who were not given an opportunity to have professional photos taken often expressed regret:

P15: I don't know if heartfelt were around in the time, but I wish they had given us the option to have a photographer come in.

P3: There's a not for profit organisation called heartfelt, that takes photos, and if I'd been given that opportunity, I would have definitely had them take photos.

Another mother explained the importance of having sensitively taken photos:

P12: knowing now.... There are people that actually do go out, they are on call all of the time and they go out to hospitals and take photos of babies that have passed. I only wish back then that there was something like that.

While each of the parents had photos of their baby that family members had taken, access to a professional photographer was considered helpful by this group of bereaved parents.

6.2.1 Reluctance to have photographs

Interestingly, several parents were initially reluctant to have professional photos taken. For example, one father recalled:

P17: they suggested heartfelt come in. We were a little bit against that at the start, because obviously we were fairly private about (baby), we protected him a lot from people.

In particular, a number of mothers explained that their partners expressed reluctance about having these photos taken:

P4: That was one thing that (husband) in particular didn't want initially. And I think that was just his way of coping, but I insisted, and I think we are both glad that we did get those now. I think he was a bit concerned about what the actual photos would be of. You know, we didn't want any photos of us at the time

Similarly, another mother recalled:

P6: My husband was a bit... the nurse mentioned it and it was very much... we don't want someone sticking their nose in and making us do poses with our dying baby.

However, this mother later reflected that she was deeply grateful to have photos of her baby:

P6: at the time, we were sort of like "no, we don't want to do that, that's just.... It would be annoying, or it's not what we need right now. But after he was gone, that's all we had.

While some parents experienced ambivalence towards having photographs taken, the majority of parents expressed gratitude for their photographs in the months and years after their child's death.

Only one parent described choosing not to keep photos that had been taken during her child's time in NICU. This mother was unique, as she was the only parent in this study who had time at home with her baby before he became ill and was admitted to NICU. This mother explained that during her time at home she took ample photos of her baby while he was well:

P5: They did take some photos. But because I had him... he was a healthy baby, and I did take a lot of photos, I chose not to keep those (the NICU photos). Because they were just too hard to look at. And I thought I don't need to look at those photos. They were just too much for me. They did take photos as well, while he was on the machine. But I didn't want that either.

She later described looking through the photos that had been taken before her son became ill:

P5: we did have that really special time with him, we didn't know that he was sick, or that he was going to catch a virus or anything like that, so I look at that to remember those times. Yeah.

In this instance, having photos of the baby was important; however, this mother chose to keep photos that showed her child while he was well and at home, and elected not to keep the photos taken in NICU that were overwhelming and confronting.

6.2.2 Quantity of photographs

Families who felt they had an adequate number of photos of their baby were typically positive about this element of their experience. For example, when asked what was most helpful in helping him to remember his baby, one father said:

P11: they made sure that you had lots of photos.

Another father described the volume of photos that he took while his daughter was alive:

P8: I think we took about a thousand photos over the just under six days that she was alive. So we definitely... we knew very early on, which is maybe different to some other parents in this situation, that she wasn't coming home with us. Um... (long pause, tearful)

For this father, recognising that his time with his daughter would be brief allowed him to prioritise taking photos to record her life.

Conversely, parents who felt they had missed opportunities to take photos, or have photos taken, expressed regret. For example, one couple explained:

P15: we didn't take any photos when we were down there (into NICU). Because, once again, we were of the opinion that he would survive. We didn't want to have photos of him with all the CPAP on...

P16: That's something I particularly regret as well. The fact that we don't have a huge amount of photos, or a huge number of photos of (baby) when he was alive in the hospital. We've got a few, but certainly you can never have enough.

While in the previous example, foreknowledge of the baby's poor prognosis resulted in a father taking numerous photos, denial of the baby's likely prognosis acted to constrain memory-making for this couple.

Another father explained that he had very few pictures of his son:

P9: no one offered to take photos or have heartfelt come in. We had no one... He

adds: we got two or three photos in total and that was off my phone, and that was really bad.

This father explained the impact that having so few photos has had on his experience of loss:

P9: You reflect back and go, oh, we should have spent more time doing this, or we should have done this, or I wish we had more photos, or I wish we had this from him. And that hurts you more.

Having a trove of quality photos to keep, to trigger memories, and to share with others was a helpful intervention for these families. Conversely, missed opportunities to record their babies lives left parents with feelings of regret. While parents made decisions around which photos to share or display, and which photos to store, most parents were grateful when as many photos as possible were taken during their baby's time in the neonatal unit.

6.2.3 Quality of photographs

Some parents described the quality of the photos as being important. Parents valued photos that were sensitively taken, and in particular, those that showed the beauty of their child without being stark or clinical. One father explained that he arranged to have the few photos he had touched up to make them softer and potentially less distressing:

P9: they made them black and white, or they made them softer, or they took the... cleaned them up a little bit, like some of the tubes or whatever else. Or they may be tubes there; it just didn't look as gaudy. Simple things like that. They couldn't do much with our photos; it was the little things that they did that meant that much.

Having photos that were less clinical and confronting was helpful for this parent. Indeed, this father felt that he could not show some of the few photos of his son to his wife until they had been altered. He only presented these photographs to his wife once Heartfelt had edited them to make them somewhat less distressing.

Another father also commented on the importance of getting good quality photos:

P8: We only had our mobile phones with us, so the quality of the photos in the first few days were as good as you can get on a mobile. One of our visitors who came brought their proper camera and we thought, "hey, leave that here please!" and it was... just the quality of the photos toward the end of our stay there were much better. So that was... I mean photos are photos, they are still a memory captured. If they can be a bit nicer, then that's great.

While higher quality pictures were preferred, this parent also identified that even the lower quality pictures had some value.

One mother, who experienced her loss 17 years prior, had only Polaroid pictures of her baby, and these were starting to degrade with time:

P14: They brought in a Polaroid camera, and we took lots of photos. They don't last forever though, those photos, they start to go a bit funny. She later adds: they're not in such great condition, and when I look back in 20 years I probably won't have them.

Having photos that were clear, sensitively taken and of archival quality was helpful for this group of parents.

6.2.4 Content of photographs

In addition to the quality and quantity of photos, the content of photos was described as important by some parents. For example, several parents described a preference for photos that were natural rather than posed:

P10: you can feel the natural love in the photos. It wasn't forced, we actually held him just before he came off life support. So he was still alive

P4: they are normal baby photos, but they are taken in a really discreet manner. They're not posed

P17: It wasn't a staged photo-shoot. It was more about just capturing us as a family.

Interestingly, a few parents also commented on the importance of candid photos, even when these captured pain and grief:

P11: there are even ones where we were crying, and stuff like that, but he got those moments. And that's the thing that I think we appreciated most, just that he actually got those moments. We can look at it now and we can feel that emotion again.

Another father explained eloquently:

P8: by far the most powerful photo (tearful). Capturing heartbreak in a photo is good. I find it good. So the most powerful photo that we've got is one where my wife is holding (baby). And you can just see the heartbreak on her face. At the time I felt bad taking that photo. But I'm very glad we did, because as I said, it kind of reminds you that it did really happen. The pain was real. And her existence was real.

This highlights the role of photographs as evidence. Photographs in this context were both evidence of the baby's existence and evidence of the very real grief experienced by bereaved parents.

Having photos that captured the details of the baby's appearance was also helpful for some parents. For example, one mother explained that the medical photographer who photographed her twins took photos from numerous angles, including photos of each baby and both babies together.

P1: he did a fantastic job. And he just took endless photos. Side profiles and hands, and put their hands together. He just did a fantastic job.

This same mother described asking the photographer at her daughter's birth to emulate the photos of her twin boys:

P1: the photos of their feet. I got... when my daughter was born, the photographer that we had for her came to the hospital, and I said "you have to recreate these photos", and she went "ok", and she did. So I've got this really beautiful frame, a three frame thing. And there's three black and white photos of feet. And you can't tell whose is whose. And even though their feet were this big (holding fingers a few inches apart) and hers were this big (holding fingers further apart), you know, with the wonders of photography and photoshop, they are all the same size and they all look the same and they are all on the same blanket. And it's normal. It's just normal.

Having "normal" baby photos, those that might be taken of any newborn, was clearly valuable for this parent.

Having photos that captured the whole family was also described as important by several participants.

P15: There is one photo where (father's) holding (twin) and I am holding (baby) and it's the only photo we've got of the family. And that is the only photo we have got of the four of us. And that was just awesome, because we wouldn't have had that otherwise. We wouldn't have even thought to take a photo of that. At the time we were just thinking about holding our children. And again, it was that unobtrusive thing that the midwives basically just said to us "look up! Smile!" and she just took the photo and we didn't even know that she was grabbing the camera. So that was certainly... that's so important that one.

P6: she took some beautiful photos of our whole family together and... yeah. They are very treasured photos.

Having photos that contained older siblings or a surviving twin was significant for these parents.

Finally, photos that captured important moments were highly prized by parents.

For example, one father explained:

P17: So there were photos of (baby) holding his mother's necklace, our wedding rings. There are photos of the first time we gave him a real bath, because he had a central line in his chest. So we gave him a bubble bath. Just capturing stuff like that – our first skin-to-skin cuddles, interactions with our families, and also the first time he was outside.

For another mother, a photo taken of the only time her baby opened his eyes was treasured:

P15: One of the ladies in NICU snapped... (baby) only opened his eyes directly after birth. And one of the ladies caught that on a photo. And he never opened his eyes again. So we never actually saw his eyes. So we have one photo of him with his eyes open, which is just really invaluable. So that was really good.

While parents valued most of the photos that were taken of their babies, photos that documented important events were particularly cherished.

Although most parents described their photos in positive terms, starkly clinical photos were confronting for parents. For example, one mother described the photos she was given of her son:

P12: the photos I have are horrific. They are not something that I can put up. I mean I do have photos up of him, I've got a couple of photos that I have up of him, but that was one thing.

Another couple described receiving photos of their baby unexpectedly in the mail, and being upset by their content:

P15: I will say on the unhelpful side, we got some photos... they took some photos of (baby) after he died. And they put him in a dress, which I was very unimpressed with. So they put him in a burial gown and then took photos. But they were taken a long time after he died. I don't know if it was an... "oh, we need to take photos" and then they put them in the post and mailed them to us without any warning. So we opened these photos of a very dead baby and it was just awful.

Finally, one father described receiving photos of his daughter from Heartfelt, and asking them to edit some of them so that the colour changes that occurred with death were less obvious:

P8: We went through a couple of rounds of "could you just touch up the colours on this one and that one?". Because there were some photos that he took while (baby) was still on the respirator, and some after if I can say it that way. And so some of the colour wasn't how we would enjoy it to look.

Having photos that were sensitively taken and that could have been of a living infant were preferred by most parents. Not only were these photos less confronting, but parents also described being able to share these more readily with others.

Interestingly, one mother explained that she preferred the photos she has of her twins after they had been removed from life support, as it was only in these photos that their faces were clearly visible. Her husband, on the other hand, preferred the photos where both babies were still alive:

P1: the photos... they had breathing tubes and they had umbilical lines and things like that. And I just hate those photos. I just hate them. I prefer the photos when everything's removed. Yeah, I don't know why. My husband likes... he likes it the opposite way, because in those photos, they are alive, when in the other photos they are dead. Whereas to me, I don't know why, I just don't like that.

For this family, having access to photos taken during life as well as photos taken after the removal of life support was helpful, meeting the needs of both parents.

6.2.5 Taking video

In addition to still photographs, a few parents also collected footage of their baby, recording short videos using their mobile phones, or using a stand-alone video camera for longer recordings:

P4: I also actually made recordings on my phone of him crying. Which probably sounds a bit morbid to anybody that hasn't been there....like just videos on my phone. Which we find really really nice to have.

P8: We took lots of videos as well. He adds: so we've got a nice HD video camera, which we had with us anyway. So we took about three hours of footage. So in percentage terms of her life, it's heaps.

For one mother, the footage of her baby helped her to recall his unique traits:

P10: Every time we did something, they were like "make sure you video tape it". So you could see... you had those moments. There's this bit where they clean out the inside of their mouth with a swab. And he used to pull the funniest faces whenever that was done. Just to capture things like that. I think the thing... doing it sort of made us more aware. You often think babies only sleep, eat and poo, that they don't have much of a reaction to things, especially being so young. But being able to do those things, and to see his reaction, and his face when you cleaned his mouth or put a little bit of moisturiser on his lips, he would start licking his lips. Or if I put a little bit of my milk into his mouth, he would taste it and close his mouth. He was a person.

While the use of audio or video recording was not a significant aspect of these parents' stories, the recent advent of mobile phones, which can record quality video, has made this option more accessible for families. Video or audio recordings may provide a valuable reminder of the baby's unique characteristics that would be difficult to capture in still photographs.

6.2.6 Displaying photographs

The majority of parents had one or more photos of their baby on display in the family home. When asked where her photos are displayed in her home, one mother responded:

P10: anywhere we can put them! On the walls, it was basically anywhere we could find a spot, we put them. In the locket I got. So yeah...

Another mother described the photo hanging in her living room:

P6: we've got a photo of our family, with the two girls and us. We've had that blown up into a big portrait. So that's on the wall in the lounge room.

This mother added:

P6: we don't make a big fuss about the fact they're in a public space, but people see them if they want and can take away from that what they want.

For these families, displaying photos was viewed as a natural choice.

Several parents described displaying photos of their lost child alongside photos of their living children:

P7: Each time one of the children has been born we have a family photo. So we've got a family photo with (sister), then we've got a family photo with (sister) and the twins, and subsequently, we have another child (son), and we have a family photo. So it's really lovely for us. And I've got one where there's four photos... A really nice one that I got all framed up with (baby) in it too. So everyone's got their baby photos up there. Everyone. So it is, it's really nice, it's very special.

P17: sitting in the back room now, I've got three canvases of (baby) behind me. I've got his footprints and handprints and a photo of him up on one wall, and we are fortunate enough to have another son, who is 18 months old, and his picture and prints are right there beside (baby).

For these parents, it could be argued that having photos of the baby included with photos of their other children was an important way of acknowledging their baby's place in the family unit.

For some parents, the need to share images of their baby was tempered with concerns about how others might feel, especially when the images were taken while the baby was critically ill, or when it was obvious that the photographs had been taken after the baby's death. One mother explained:

P18: if anybody does ask me I'm like "yes"! (mimes passing a book to another person). I know some people don't really... I know some people find that a bit confronting. But they are beautiful photos. They are absolutely beautiful photos.

Similarly, one mother commissioned a portrait of her daughter, which was painted using a photo taken in NICU:

P12: We got that portrait done of her from the photo, from one of the photos the nurses took that's got her toy in it. So it was really helpful to get that done actually. Because all the photos of her alive have tubes and wires and things, and no-one really wants to show photos of their dead baby to people. So that was helpful for us.

For this mother, having an image of her daughter that clearly showed her features but that was not overly confronting allowed her to display her daughter's picture without fear of upsetting others.

6.2.7 Impact and significance of photographs

All but one of the parents expressed gratitude for the photos that were taken during their child's stay in NICU, whether these were taken by staff, by professional photographers, or by the family themselves. For example, one mother reflected:

P18: I have heard since of people that don't have any photos and I feel really bad for those people, because that's the one thing that I can hang onto. We only had him for a week and if I didn't have stuff to look back on it would be horrible. You know because you don't bring a baby home from hospital, so it's like only a couple of people really met him. But he is still a big part of my life. So I love those photos.

She later added:

P18: But he does exist for me still. And I think that's the part where the photos really do help. Sharing something that happened to you or in your family with other people that didn't meet him. I really do think it's really important.

This highlights the role of photographs as evidence of the baby's life, and of the parents' roles as mother and father, especially when few people interacted with the baby in person.

For another mother, having photographs of her son allowed her to share him a family member who did not understand her loss:

P12: (Partner's) uncle wasn't around at the time that we had (baby). So a few years go by, and in his head, it was oh well, you had a baby and it died. Big deal, he was only born at 27 weeks. What he didn't grasp was that he was an actual baby. That he was born alive, and he was a baby. He wasn't just nothing. And when I showed him the photos, it changed everything with him and how he thought. I think it's important for families to be there, to... I don't know, but it is important.

Similarly, another mother explained the importance of having photos on display:

P4: That's what we find with the photos especially. I think a lot of people like to think that, you know, we just had a miscarriage. And you know, leave it at that. Whereas by having photos up, and especially the hand and foot prints, because people can see, well he had hands and feet!

Sharing or displaying photos and other mementos helped these mothers gain a sense of acknowledgment, both of the baby's life, and of their own loss as a legitimate bereavement.

Several parents who had had children subsequent to the death of their baby, or whose children were very young at the time of their loss, explained that the photos were also important as a way of introducing the lost child to their siblings. For example, one mother lost her infant daughter when her firstborn was only two. She explained:

P3: I'm kind of glad that we've got those photos now, because we will be able to show her some kind of photos to say "this is your sister"

Another father described showing his son an album made with photos of their baby who died when their son was very young:

P9: we have subsequently shown our son in the last year and a half, that book about (baby).

Having photos allowed parents to introduce the lost child to surviving siblings in a tangible way.

Finally, for several parents, having photos of their baby acted to confirm that the baby did exist and was real. For parents who had little time with their child, or who had few tangible mementos, photographs acted to confirm the child's essential reality. For instance, one mother explained:

P5: I've also got photos up on my wall. I've got a big photo of him with all my other... with photos of my other children as well, and then I've got one of just him on my TV. It's just my way of remembering him and sort of... and remembering the happy times...that it really happened.

This was especially important for a few mothers that were very unwell at the time of their child's birth and death:

P6: I guess for me having the haemorrhage and the general anaesthetic and the whole trauma of that on it's own, let alone your baby dying, that time... being in a drug haze of having a caesarean, they are really important for me, because that part is so foggy for me. Because I was so sick myself, that bits of it, I still don't

remember bits and pieces of it. And every now and then I'll say to my husband "how did this happen"? or he'll talk about something and I'm like "well I don't remember that at all". So yeah, the photos are really important to me. And I guess when (Baby's name) was dying, I was so terrified that I would forget him.

She later added:

P6: he'd never been home, he didn't have anything at home that was his. So I think that was my biggest fear. And so the photos sort of relieved that stress for me. That we had something to remember him by.

Having photographs provided reassurance to some parents that their baby was a real person and would not be forgotten.

6.2.8 Summary: Photographs as an element of memory-making

For parents in this study, photographs taken of the baby before or after death were an important aspect of memory-making. In the simplest sense, photographs provided a tangible reminder of the baby and allowed parents to view their baby's physical features and characteristics at will. More importantly, photographs acted as evidence of the baby's existence, long after the baby was physically gone. Photos that captured the family as a whole, and particularly photos that captured moments of parenting, such as holding or bathing the baby were uniquely treasured and provided evidence of 'Being a Parent'. Being able to show photos to friends and family helped to enhance this aspect of memory-making, enabling parents to effectively share their baby with others who may never have met them in person. This allowed parents to establish their baby's position within the family, and to claim their own role as parents.

6.3 COLLECTING AND CREATING MEMENTOS

In addition to photographs, all of the parents had at least some items that could be described as keepsakes or mementos. In this group of bereaved parents, the most commonly described mementos were hand or foot prints, locks of hair, cot-cards or hospital ID bracelets, as well as items that ‘belonged’ to the baby, such as blankets, clothing the baby wore, or toys that were purchased for or given to the baby.

6.3.1 Handprints and footprints

All of the parents received a handprint or footprint taken from their baby. Most commonly these were done in ink, by pressing the baby’s foot or palm into an ink pad and then onto a piece of paper or card.

P8: We did just the ink footprints, which worked fine. It was just ink and card supplied by the (hospital) NICU. So they’re nice. We made a couple of footprints and a couple of handprints

P6: They also did hand prints and hair locks and... did little ink prints on paper

For another mother, having her baby’s footprints serves to remind her how big he was:

P4: it’s just really nice to just remember how big he actually was, not just in photos

Footprints were routinely collected by nursing staff and given to parents, although some parents were involved in the process of creating these mementos.

Interestingly, several parents commented that having imprints or casts of their baby's feet was preferable to two-dimensional prints taken with ink or paint.

P8: But what we found even more impressive now, is the imprint kits that we bought. So I assume that you are aware of what I mean by the imprint kits. He adds: they are the thing that I touch on a day to day basis the most. And they are definitely the most physical reminder.

The tactile nature of imprints seemed to make them more meaningful for parents than traditional ink-based prints. For example, one couple explained:

P16: there are plaster casts of (baby's) feet in the memory box as well. That was part of the box that the hospital provided, which I thought, something that's tactile, that you can touch and feel is really cool.

P15: And we take it out and we hold on to the feet, which is quite cool.

Similarly, one father reflected:

P8: Those ones are 3D, so you walk by them and you can feel the little crevices in her footprints and the like.

Another mother who did not receive imprints argues that all neonatal units should have kits that contain all of the necessary elements for the collection or creation of mementos:

P1: Like, you know, you can get hand prints made. And I think that should be in the kit. I think they should just be there. You know the little plaster... the little five-minute ones that you mix it up and go "boop boop" (mimes pressing hand into

plaster) and they're all done? I would love some of those. I would just adore some of those. But I didn't know you could do that.

Similarly, another mother reflected that being offered imprints in addition to ink-based prints would have been good:

P13: At times I've thought I would have liked you know, the moldings of her feet, or her hands. I don't think it was offered. Yeah.

While both of these mothers felt that they had received a number of mementos, the missed opportunity to create imprints was a source of regret. The tactile nature of imprints made them preferable to ink-based prints, although parents who received both were grateful for these.

6.3.2 Cot-cards and ID-bands

In addition to imprints, the name cards from babies' cots were described as important mementos by several parents.

P15: they laminated the name plate for him. And all these things we've now got in a memory box. Yeah, it was just fantastic. They just went out of their way to create memories for us, which is really good.

In particular, these cards were seen as an acknowledgement of the baby's identity and importance:

P18: Even when he was first born they made up a sign with his name and that is pretty much straight away. She adds: I think even then they had put his sign up. And I thought oh. I was fearing the worst, but he may not be with us or maybe not

that long. Or that they weren't going to count him. But the fact that they made up a sign with his name it felt hopeful to me. I thought they must obviously think... He is our baby

Similarly, one father reflected:

P8: Her having a nametag on her crib was very important. She's a person, she's got a name.

This underscores the power of some mementos to give the baby a social identity and the impact that small gestures made by staff have on families

6.3.3 Clothing

The majority of parents had at least one item of clothing that their baby had worn, and these items were seen as valuable mementos. For example, one mother brought out her baby's memory-box to show the interviewer. Gesturing at her baby's clothing, this mother explained:

P13: they are probably more meaningful because they were things she wore.

In several instances, the babies were too unstable to be fully clothed. However, these families were typically given the NICU-supplied beanies or hats that the babies had worn:

P1: they gave me their hats that they wore in the NICU.

P9: There was a beanie that he was wearing all the time in the actual NICU that we wanted to keep. That uh... I was pretty adamant that we needed to have that, and I asked them to go and find it. Find the right one.

For one mother, no clothing was provided as the baby was not dressed while in NICU, however, staff had added a clean premature-sized nappy to the baby's memory box.

P2: they even included one of his nappies, an unsoiled nappy. I mean it was teeny teeny tiny, but I mean, I don't know if other people would find that bizarre, but I thought that was a nice little touch as well. Because he had worn that. She adds: yeah, because while he was in the NICU he wasn't in any clothes apart from a nappy. So that's all he wore, so....

Clothing or other items worn by the baby were valued as mementos by parents. These items acted as tangible evidence of their baby's existence.

As with imprints, the sensory nature of clothing increased its significance as a memento for parents:

P13: I think that was helpful. Just to have something that she's worn, that you can touch and hold.

P4: we kept the clothes that they did have him in. And that's really important. I've sealed them up in a bag, just because to us, they even smell like him. So that's something that's really, really important. You know, the knitted outfit. Just knowing that he wore it.

Having items of clothing that the baby had worn, and that could be felt and smelled was described as being helpful by the parents. Conversely, one mother regretted not having an item of clothing from her baby:

P15: we didn't think to ask... he had a beanie on all the time and we didn't think to ask about the beanie or anything else. So it really was... what we got was the photos, the footprints, the wristband and the signs from his cot. And they kind of went through and threw in anything they could find that would create a memory for us, which was great. But there were little things, like I would have liked to have had his beanie.

Despite acknowledging the number of mementos she received, not having an item of clothing her son had worn was a source of disappointment for this mother.

6.3.4 Toys and blankets

In addition to clothing, several parents had also kept other belongings, such as toys that were made or purchased for the baby, or that were given to them during their stay in NICU:

P1: they'd given them two tiny little teddies, like about this big (holding fingers a few inches apart) that had sat on top of their humidicribs and stuff, and they were in the boxes. So that was really good.

Having items that belonged to the baby was also a way of maintaining connection:

P13: So we did bury her with some of the gifts, but we kept some of them too, so that's a connection to her as well.

For another father, sharing his first son's toys with his second child has been helpful:

P17: he had a lot of toys. And it sounds funny, but as you have other children, you hand the toys down. So his little brother has got a heap of his toys and we have

this saying, you know “he won’t be happy that you’re playing with that!” and that sort of thing. (laughs). And obviously, when he’s older we want to make sure that he understands that he’s got a brother. And yeah, what he was like.

For this parent, being able to pass some of the baby’s toys onto his brother has helped create a connection between the children that might otherwise not have existed.

Parents also described keeping the blanket that their baby had been wrapped in as a memento. One mother explained that she was allowed to keep one of the hospital’s blankets that she associated with her son:

P6: They’ve got a collection of sort of polar fleece blankets as well. And there was this one blanket that we always had (baby) in when we were giving him cuddles and stuff. So they let us bring that home.

Similarly, when asked if he had brought anything home from the hospital that reminded him of his son, one father responded:

P17: We had wraps that he used to lay on, or that were over the top as a blanket, which we purchased, but we packed up for him.

Having items that belonged to the baby, or that had been in contact with the baby, was seen as helpful by parents

6.3.5 Lock of hair

In addition to footprints, clothing and belongings, the majority of parents received a lock of hair as a memento of their child.

P5: A lock of hair. Yep. Yeah, they gave me a lock of hair.

The lock of hair was frequently cut from the baby by nursing staff, and was included in a memory box or memory book collated by the staff:

P2: They did give us this memory box, and that had his hand and foot prints in it, and it had a lock of hair

P4: the hospital staff collected up a few bits and pieces for us and put it all into a little book. Um... it includes some hair that they cut from him.

One father explained that the staff kept hair they needed to cut to obtain access to scalp veins:

P17: he had head cannulas at some stages for transfusions etc, so he had this long blond hair and obviously they had to take a bit of his hair off to put the needle in. So the nurses made sure we got three lots of his hair in a little sample container. So they made sure they did that for us.

Some parents described having a piece of their baby's hair as important. For example, one mother described asking her nurse to collect a piece of hair from her twin boys after they had been transferred to the mortuary:

P1: She went and did that for me. So that was really, really good. That was really important to me. Like yeah... hard to get, but really, really important. Yeah, that was really important.

Another mother described the lock of hair she received, which was taped to a piece of card:

P13: I would have liked some hair that wasn't stuck down (looks at hair sticky-taped into memory book). I mean that's just something I've thought of from time to time. I don't know, something to touch I suppose.

While this mother valued the memento she had been given, the way it was presented meant that it was less tactile than it could have been.

Finally, one father argued that collecting a lock of hair should be standard practice unless the parents are actively opposed:

P9: you are never actually going to have that time again with your son or daughter, or you are never going to get the photos or the hand prints or the cut of hair if they've got hair on their head. And they are the key three important things that you need to have.

For these parents, having a lock of hair was considered valuable, especially if this was presented in a way that preserved the tactile nature of the memento.

However, hair was more controversial as a memento than items such as photographs or footprints. One mother explains that she resented not being asked before the staff cut her baby's hair:

P14: Just being asked before they cut hair. For some people, they want the hair, but for me I didn't like that at all. He didn't have a lot of hair, and to think that they just cut it...

This highlights the individual nature of parental preferences and the need to involve parents in the process of collecting or creating mementos. It is also possible that taking hair from the baby was a form of boundary violation for some parents, as taking a lock of hair meant physically altering the baby's body in a way that did not occur with other types of mementos.

6.3.6 Cards, journals and poems

Finally, several parents received either cards or journals as mementos. For example, one father described the daily journal written by the nursing staff:

P17: "the best thing with that, the nurses there, they have like a daily diary... it's like a scrapbook. Where the nurses would detail what they did that day, or what (baby) did to them. Just experiences, or explaining things. They designed it so...the aim is to have your children leave the hospital, and then, later on, you can look back at that time and go "oh, this is what happened here" or "this is what this nurse did with you". Yeah, they really decorated it well, it's literally like a scrapbook. So that was just something little that we appreciated, because it

actually showed that caring factor. Not just coming in and doing a shift and leaving.”

The same father was given a birthday card on behalf of his son:

P17: It was my birthday, I remember, and one of the nurses saw that it was my birthday, and she made a birthday card from (baby). And she did his footprints and yeah, it was really beautiful. It's amazing things like that by this one nurse.

For this father, the time and effort put into the journal by the nursing staff and the gesture of the birthday card indicated that they cared about his son and about the family as a whole.

For another couple, journal entries written from the perspective of their baby were especially meaningful:

P11: it basically said “on the (birth date) at this time, I was born, I couldn’t wait to meet my mum and dad”, and it had all the doctors and nurses and stuff like that. Um...

P10: “I could tell mum and dad loved me, because they didn’t leave my side”... it was really... it was nice. Because it sort of gave him a voice.

P11: and it was good too, because at the memorial, they were able to read that out..

P10: yeah, my sister wrote it on the memorial invitation. So it sort of gave everyone else a little bit of insight into what he was and who he was.

For this couple, this small story helped to give their son a unique identity, not only for them but for those attending his memorial service.

6.3.7 Memory boxes and memory books

The majority of parents received photographs as well as some or all of the mementos described above as part of a memory box or memory book. These boxes or books are often supplied to NICUs by a range of charity groups and are generally designed as a way to contain and present photos and mementos. Several parents described receiving a memory box or book from staff:

P5: It's more the box... what they gave me at the hospital, so the handprint and the footprint, I've got some clothes that he wore, like a wrap. I've got his belly-button clamp... I've got that type of stuff.

P1: The hospital gave them to me. The nurses did up some books, with their footprints and their hospital bracelets and they gave me their hats that they wore in the NICU. She adds: they'd put as much of their things, that they had touched in their life, in the box.

P4: The hospital staff collected up a few bits and pieces for us and put it all into a little book.

P12: They came in with this bag, and in the bag was his life support tags, his blanket... I've still got them to this day....They collected everything for me.

Memory boxes or books were a standard element of care for these families and were typically appreciated.

A few parents commented on the box itself. For one mother, the tacky cardboard boxes she was given were disappointing:

P1: they were cardboard, and they were just.... (laughs) a bit nanna-ish. And I think that problem is being addressed anyway. The treasured babies have taken a different turn, so they've fixed that up. I know the boxes that are being provided now are beautiful wooden boxes, with very gorgeous paintings on them. She adds: Like they were just these cardboard things that... like a... bad pinterest. (laughs) you know how you see "pinterest" and then "nailed it"... like, so not! (laughing). Sorry!

For other parents, the care taken in making and decorating the boxes was appreciated.

For example, one couple explained:

P16: we've got the memory box.... The memory box is sitting on a shelf in our living room out the back, below the painting with a few other things. I thought that the memory box itself was really cool

P15: yeah.

P16: Not only the contents of it, but the box itself.

P15: The hospital, and I don't know if all hospitals do it, but they have a wooden memory box and they do painting.

Receiving boxes or books that were created with care was meaningful to parents.

Finally, parents appreciated memory boxes and memory books that had been personalised to their baby. One mother commented that the box she was given felt overly generic:

P7: I just think back to all of those resources... it just seemed pretty um... bland and.... You know, it wasn't very personal or anything like that...

Interviewer: generic?

P7: yeah, generic is a good word. And I guess there was the capacity to maybe make it more personal

She later explained:

P7: I just got the sense that, eh, this is a resource that we go and get out of the cupboard, and we give it to the parents we need to give it to. You know? There wasn't... I felt like they did the best with what they had, but I look at that and I'd go, "well there's nothing about that folder that I link with (baby)." That I really want to treasure and keep. I'm keeping it because you keep whatever you have of your child, because it's so limited, I mean it's in a box this big. That's a child, a person's life. But you know, I look at it and I think, oh, it's not particularly...

Interviewer: it's not about him?

P7: no...no, not really, it's just a generic resource.

For this mother, the generic nature of the memory box made it less meaningful.

Conversely, one mother brought out the memory book that was created by the staff for her baby during the interview. She showed the interviewer the book, and pointed out the captions added to photos and the handwritten comments alongside the physical mementos:

P13: I guess it's sort of like scrapbooking sort of stuff that you would normally do for a baby. And that that they did that for us was helpful.

Having memento books or boxes that acknowledged the unique attributes of the baby and were personalised was valuable, while feeling that they had been given a standardised or generic memory book or memory box was less helpful for parents.

6.3.8 Displaying mementos

As with photographs, many parents described having one or more mementos of their baby on display in their home. For example, several participants had shelves or display cases in their homes that held mementos collected or created in NICU:

P2: I've now got at home a display cabinet of all the things that we've got. And in there I've got his lock of hair, and I've got his hand and foot prints.

P15: They have a volunteer at the hospital who makes bears for twins. And every time a twin is born she makes bears. So that's a NICU thing, but she made bears for (baby) and (sibling) and the bears stayed with them the whole time they were in hospital. So they came home, and they still have pride of place on our mantle. They are just little teddy bears, one in pink and one in blue.

More commonly, parents had footprints or artwork hanging on walls in their home. For example, one father explained:

P9: We have a little thing up on the wall for him, that's just got (name) and then his handprints and footprints and the dates.

Similarly, another mother described a drawing she had made from a series of photos taken in NICU:

Interviewer: is the drawing something you've shown other people?

P14: Definitely. It's on my wall in the lounge room. So I've always been very proactive in making sure he's never forgotten. So yeah. It's in the lounge room.

Finally, one mother discussed the significance that having mementos on display holds for her:

P1: And they are tangible, they are there. They are not here, but I've got them. And they are a part of our family. They are part of everyday life. They are in our hallway. I walk past them every day. I've got to dust the bloody things (laughs) but you know... (laughs). That sort of stuff. Yeah. If I didn't have any of that, it would just be... I had this stay in hospital and I came home. That's all it would be. And that's not what it was. So yeah. It's important. Very important. Yeah.

For these parents, having evidence of their baby's life on display in the home was seen as helping to honour their baby's memory, while also validating their baby's existence and role within the family.

Some parents also described being able to share their mementos with members of the family as a way of acknowledging their shared grief:

P10: Because even though the parents are the main ones that are affected, it does affect the whole family. (Baby) was the first... so many firsts... on (husband's) side he was the first great-grandson, and the first grandson, and on my side, he was the first great-grandchild and the first grandchild. So for our parents to lose him, for our sisters to lose him, to lose their first nephew... because we only have one sister each, so they all went through the grieving process. And just to be able to give them photos of him, and go, look, he was here! And let them see him and be with him, and have photos with him themselves. And I know those photos are in pride of place in each of our families' homes.

Another couple described making cards using the baby's footprints to give to the baby's grandparents:

P11: we gave them as cards...

P10: one to my mum and one to his mum. So they were able to have them. Just... our mums are a bit sentimental. They've even still got ours (baby footprints). So just for them to sort of add that to ours, was enough for them.

P11: it's also a good way for reminders for others as well in the families, just to give them that... I don't know

P10: that little piece of him.

Being able to provide photos or other mementos to family was seen by these parents as a way of acknowledging the grief felt by other members of the family and supporting others to remember their baby.

6.3.9 Storing mementos

While all parents had at least one photo or memento of their child on display, several also had items that they had stored away and that were rarely taken out and looked at. For example, one mother discussed the memory box she was given:

*P3: They were very helpful. But I haven't looked at those for a very very long time.
(tearful)*

Similarly, another mother explained that although she has a number of mementos on display, she chooses not to look at the memory book that the hospital created as often:

P4: It's really nice, but I don't tend to get it out very often, but it is something that we've kept.

When asked why she doesn't look at the book often, she explains

P4: the other things that we've got out are kind of... if you didn't know any better, they are anything that any normal person would have in their house of their baby. Whereas the book is a little more hospital focused.

For this mother, photos and footprints that did not remind her of her son's illness were easier to appreciate than more the medically-focused items, such as chest leads and saturation probes, which were included in her baby's memory book.

Another father explained that he has mementos and photos on display, but has chosen not to look through the memory box provided by the hospital:

P8: a little memory box from the hospital, so they did put that together, with a lock of hair and that kind of stuff. The tag from around her wrist. I think that its stuff that we want, but I've never opened that box. So while it's... they said do you want us to put this together, and "yes!", with some photos of us etcetera, but in the scheme of things, it's... I am glad that we've got it, but I've never looked at it once.

This theme of being glad to have mementos but being selective about which were displayed or viewed was common among parents.

Several mothers also commented that while they did look at the stored mementos from time to time, their spouses chose not to:

P6: he knows it's there, and he likes to know it's there, but he can't bring himself to look at it.

P7: he doesn't mind at all that the photos are up. He would never go and look at the treasure box or anything like that.

These mothers expressed an awareness or acceptance of the different coping needs of their partners.

While some parents had stored their mementos and rarely looked at them, they still expressed the importance of collecting and creating those mementos in the brief window of opportunity available:

P4: I think they did a great job in the circumstances. But it really is all we've got left. So for us it's really important

P2: I've had another child, and you know, I get his hair cut all the time, so I can take whatever locks of hair I want, but with (baby) I'm never going to get to do that. So I think the hospitals should just be mindful that this is it. This is all we are ever going to get.

Parents described their mementos as valuable even when they chose not to have them on display, or looking at them often, emphasising the importance of collecting evidence of the baby's existence during their brief time in the NICU

6.3.10 Creating new mementos

Finally, for some families, the items collected or created in hospital provided a basis of the creation of new mementos. For example, several families used the footprints or handprints collected in the NICU to create jewelry or cufflinks that could be worn as a reminder of the baby:

P10: I found when I received the bracelet, and I had his hand and foot print on me, I just felt more complete. Like I've got a little bit of him with me.

P8: Actually, I am wearing (baby) cufflinks at the moment. My sister bought me some cufflinks. So it's nice just having little reminders throughout the day of her being there.

P9: those little handprints and footprints we got in that booklet, which didn't seem... we didn't know what was going on at the time, but we are so grateful (nurse) did that. Because now I have cufflinks that have been made with those

handprints in them. Which is probably the most amazing thing. I wear those pretty much every day at work. So I have both my boys with me every day. Because we got a replica pair for (sibling). So I have one of (sibling) and one of (baby).

Having the capacity to create and wear items made with the hand or footprints of the baby was meaningful for parents who described this as a way of carrying their baby with them.

One parent also described creating a piece of art from her baby's footprints:

P1: Like, the footprints, they did ink footprints. I've taken those, and I've got my daughter's ink footprint, and I've made my husband do an ink footprint and I've done an ink footprint, and I've sort of... I'm a bit of a pinterest freak too... (laughs) love it. I've made a family tree, and the feet were the leaves. She adds: that's hanging in our entry way. And it's like, that's our family.

For this mother, incorporating the mementos collected in NICU into a piece of art that involved the whole family was a way of confirming her baby's place within the family.

While parents were largely positive about the mementos they received, a few parents were given items that were distressing or unexpected. For example, one mother described receiving a health record for their child as an upsetting reminder of all of the milestones that would never be met:

P4: after (baby) had passed away, we got given his green book, which is where they record all the vaccinations. Which at the time was really upsetting because it's like... you know it's from birth to school age. And seeing that we got given this

book that had the first page completed, and then.... We knew we were never going to complete the rest.

She later added:

P4: it's so obvious that one page had been filled out, and you've got about 40 other pages to document things on that... they are not milestones we were going to reach (tearful)

This mother later reflected that while she found this item upsetting, other parents might want it.:

P4: you kind of get home and open it up and think... you know why were we given this now? And I know that it's really hard, because some parents would probably want that. But for us, it would have been We would have much preferred to have been given it later, or even if it was just sealed, or, if we just knew what it was.

Few parents described receiving mementos that were upsetting, however these experiences highlight the unique nature of each parents' grief and the need to take care with timing when providing mementos to families.

6.3.11 Impact and Significance of Mementos

As with photographs, parents described their mementos as being significant in a number of ways. Perhaps most importantly, mementos acted as proof of life for families whose baby was known by so few people. For example, when asked what impact her mementos had on her experience of loss, one mother explained:

P2: And I mean, for me, I can go back and look at that. And see that my baby did exist. I have proof that he lived. She adds: and it's kind of like a validation for me, that... you know, because stillbirth and neonatal death is such a taboo topic, and people don't want to really talk about it.... So for me when I'm having a particularly stressful day and I don't have the support, I can at least go back and look at the photos, and I can look at his footprints and go "you know, he was here and he mattered to me". And I have all this proof.

Similarly, another couple recalled:

P11: yeah, with the box. Yeah, it was sort of like... we just went into a big slump, because it just didn't feel real. It was almost like we didn't just go through all that, really.

P10: and so it wasn't until we got those certain things, the memory box and the photos. It was more that... he did exist. He was alive.

The mother from this couple later reflected:

P10: When you have these things, and these little reminders, it just makes you feel a little bit more sane. Like, I'm not going insane. It did happen.

In this sense, having mementos was significant for parents as they acted as evidence of the baby's existence. For parents, the brief time with their baby was often described as feeling unreal, and having tangible items helped to reassure parents that their experience of loss had really occurred.

Having tangible evidence of the baby's existence in the form of clothing, handprints or hair also acted to provide a social identity for the baby. One mother described the memory book that staff created for her:

P13: there are some photos that they took where they put things that people had given (baby) in the crib with her. And they wrote little captions, I suppose, and I think they were... they just made it seem like she was really alive. Because really, she wasn't really alive for long. But it made it seem like she had a personality or something like that.

For other parents, having "normal" mementos acted as an acknowledgement of the baby's life and helped to cement their place within the family:

P1: It's just normal. My daughter has her teddy bear, my sons have theirs. She has, you know, I have her hospital bracelet, I have their hospital bracelets. It's just a normal.... I don't have one child, I have three.

Mementos held significance for parents in a number of ways. They acted as evidence of the baby's existence, as a way of asserting a social identity for the baby, and also helped parents to integrate the lost child into their family.

Mementos also acted as an aide memoire for parents. For example, one father explained:

P17: having those mementos or photos can actually take you back to the moment, which is good. It's a nice change. And also, four years down the track, it's good to have something that reminds us, so you are not relying purely on your memory.

Similarly, one father explained:

P16: it also gives you an opportunity down the line... because often with grieving and stuff like that, you sort of worry about forgetting and things like that. But because they've given us all these things to help us remember...

Having mementos and photos reassured parents that they would not forget their baby and helped them to recall the events around the baby's birth and death.

In particular this was important for mothers who were seriously ill for part or all of their baby's life:

P13: I was not conscious for much of it. So I think that's why the memory-making things, the things that we did get were so important. And her life was so short.

P6: that part is so foggy for me. Because I was so sick myself, that bits of it, I still don't remember bits and pieces of it. And every now and then I'll say to my husband "how did this happen"? or he'll talk about something and I'm like "well I don't remember that at all". So yeah, the photos are really important to me.

These mothers relied on the photos and mementos that were gathered for them during their baby's brief life as a way of processing what had occurred. As such, mementos and photos were particularly valuable where the parents' own memory was unreliable due to their own physical condition.

Finally, some parents identified that the mementos they have acted to soften their grief to a small degree:

P10: the memories and the time that the hospital spent to give him to us was just so... it was so much easier for us to cope with it all. I mean it doesn't take the hurt away. But it sort of just protects you a little bit more from it.

Another mother explained that without the typical possessions left behind after a full life, photos and mementos are important in helping parents move through their grief:

P18: I mean I lost my father, and that was a hard process, but I think when you have lived a life and you have memories of that person, you know, you knew their quirks you can sort of rely on your memories almost more than anything else. And then that helps you move through. But when you have all this hope for a baby that's coming and then to have that dashed. And in some cases people haven't had anything to hold onto. And because there is no memory other than perhaps traumatic memories... Yeah I love my photos.

Finally, describing the impact of mementos for her and her husband, one mother explained:

P10: We were... we ARE parents. You know, and we spent every minute of his lifetime with him, and showered him with love, and that's all a parent can really do.

Similarly, one father asserted:

P9: regardless of what type of acknowledgement that you do have, whether it's a tattoo, whether it's cufflinks, whether it's something on your wall or whatever, acknowledgement is probably the most critical thing for any person. And it's critical for all of us. So we are both mum and dad, and this person existed, even if it was for one second, or was born, or with (baby) it was two days.

Photos and mementos were significant to parents for numerous reasons. They allowed parents to recall events and to process them over time, and they served to validate the baby's existence and to provide them with a basis for social identity, and they provided affirmation of participants' roles as parents.

6.3.12 Summary: Collecting and creating mementos as an element of memory-making

Parents in this study possessed a range of items that could be considered mementos of their baby. Items such as handprints and footprints, items of clothing and personal items such as blankets or toys were most frequently described. Parents were at times involved in collecting or creating these items, although frequently this activity was suggested or initiated by staff. Parents were typically grateful to have a range of mementos, although thought needed to be given to involving parents in the process of memory-making, and permission given before staff collected items such as a lock of hair. Having mementos provided further evidence of the baby's existence and provided a basis for the development of a social identity for the baby that had salience for parents and could be shared with others outside the immediate family.

6.4 INVOLVING OTHERS

6.4.1 Others “meeting” the baby

For the parents, creating evidence went far beyond the collection and creations of artefacts, such as photographs or footprints. Parents also described involving others as a way of confirming their baby’s essential reality. Involving others was a strategy used by parents to ensure the baby’s existence and significance were acknowledged and remembered by others. In addition, involving others allowed participants to receive acknowledgement of their own role as parents. Parents described several strategies for involving others: having others “meet” the baby, involving others through mementos, rites and rituals, and talking about the baby to others.

The majority of parents had at least a few people visit them and their baby during their hospital stay. For many parents this was suggested by staff when the decision was made to limit or withdraw active treatment:

P14: We were able to bring... my parents came in, and my mother-in-law came in. So they certainly allowed family to come in.

P15: We were told that we could bring in whoever we wanted to. So we ended up calling my parents and (husband’s) parents.

P2: All of our family were allowed to be there. So they gave us the time to call our families for that support.

P6: I mean we were... (baby) was lucky he got to meet lots of my husband’s family are in (city), so he got to meet pretty much most of his aunties and uncles. My

mum and my sister came down for five days. So you know, we were lucky he met most of the important family members

P7: So we got our parents in, and got (sister) in, and just, you know... everyone just got to... the grandparents and (sister) just got to say goodbye.

Other parents described having family and friends visit after the baby had died:

P12: We had a few family members in (place name) when he was dying, and when he actually passed away, but then we had other family, like my mum and other family members that came to the hospital hours after he had died.

Having other people “meet” the baby, whether this occurred before or after the baby’s death, was described in positive terms by parents.

Parents who did not have many people involved during their NICU stay often described feelings of regret around this:

P13: And I think probably that’s one of our regrets, and it was the circumstance we were in, but I know lots of people who have gotten everyone in to meet the baby, whether it’s after the baby has died or before. Now obviously she was in NICU, so that probably wasn’t really going to happen, but even after she’d died it probably could have been something that we could have done. And for a long time we did struggle with the fact that she wasn’t really real for anyone else. And she really wasn’t. She was born and then she was dead and not many people saw her. If I’d known then, I would have asked my friends to come in. yeah, I guess we felt like for a lot of people it was easy just to move on. Lots of people acknowledge her, but you know, for some people it was just something that happened.

This highlights the role of involving others in creating lasting evidence of the baby's existence outside of the baby's immediate family. Where parents could share memories with others, the baby was 'real' for those people, and parents felt that the scope of their loss was acknowledged.

Interestingly, several parents commented that the thought of having others visit was not a priority during their baby's time in NICU, but that after their loss they were grateful that others had been able to meet their baby:

Interviewer: Was it important to you that other people got to meet him?

P15: at the time, no. Afterwards yes. At the time we were just basically coping.

Afterwards that was really amazing that they all got to meet him. I would have wished that we had invited more people.

Similarly, one mother was asked whether it was helpful to have her parents visit while her baby was alive, and she responded:

P4: in hindsight, yes. At the time I think we wanted as much time just the three of us as possible. You know, that was really important. But in hindsight it is nice that somebody did meet him.

For other parents, balancing time alone as a family with time visiting with others was important:

P8: And we had lots of visitors. We tried to cram all of our visitors into two days, so that we could have the rest of the time for us. But yeah.

While parents in the midst of their loss focused on spending time with their baby and were at times reluctant to involve other people, the parents were glad in hindsight that other people had met their baby.

While parents were typically happy with their decision to involve others, a few parents commented that having others meet the baby was a mixed experience as some of the extended family members found the baby's condition distressing:

P17: we had a mixed reaction from family members. To us, as I said, it was the norm. We knew (baby)'s severity, we knew what we were up against. But I think it was very confronting for a few family members. They couldn't handle the situation. Where other family members, you could just see the love in their eyes. All the family love (baby), but I guess it was just a very confronting situation. For us as his parents it was hard as well, because you felt helpless a lot of the time as well. But yeah, I guess it was good to have family there, but it's hard too

P15: Certainly now looking back, it was pretty amazing that people got to see him. And that is definitely very important. Just at the time, I guess part of it was that we couldn't cope dealing with other people. Because they obviously didn't know what to say to us, didn't know how to treat us, didn't know what to do.

This highlights the need for staff to provide support for extended family who are visiting, as well as for the parents during such visits.

6.4.2 Talking about the baby

In addition to having others meet the baby, parents described involving others by speaking about their baby often. For example, one mother explained:

P10: I've got a friend who said, "don't rob yourself of having a baby". Be able to talk about him, and if someone asked how we were at that time, go "oh, I was in hospital having my baby" and show photos. Don't mention that he passed straight away. Give yourself that moment, to go "yeah, I have a baby, he's beautiful and he's gorgeous" and if it goes further, then probably say "yeah well, he passed". But I'm still enjoying all these moments of it. You can't rob yourself of that, because you do get robbed of a lot of things, a lot of experiences. So you've got to be able to talk about his birth to other people.

Similarly, one father related his experience:

P17: I have one mate who just said "tell me about him, what was he like". And that's what you need. You need people to be able to go yes he was here, and he meant something. It can be achieved very easily, depending on friends and their experiences, they will be very stand-offish, and I guess it's more that it's hard for them rather than you. But yeah, as parents we want to talk about him.

For these parents, being able to speak about their baby with others was a way of acknowledging, and receiving acknowledgment, of their baby's existence and importance and their own role as parents.

6.4.3 Involving others through mementos

For some parents, being able to share mementos with others was a way to involve others with their baby after their loss. For example, when asked how having mementos impacted on their experience of loss, several parents explained:

P4: it sounds really morbid, but we can put it in peoples face, and we can show them that you know, he had hands and feet. And you know, by having his things in the house, and having all those bits and pieces that we collected, it does validate the fact that he was alive. And the fact that he did exist.

P12: I suppose explaining to people that he was born, he was a baby, he was my baby. Yeah, definitely to make people acknowledge him. Yeah. To acknowledge that he was actually real. That he was born, he was here.

Another mother also described this as important:

P1: I can share them with people. People who never met them, they can meet them. And I can... I can use them. They can be part of our family.

Being able to share mementos with others helped parents to gain a sense of acknowledgement, both that their baby existed and that they themselves were parents.

6.4.4 Involving others through ritual and faith

Six of the eighteen parents in this study described engaging in faith-based rituals with their baby, such as blessing, baptism or christening. For some parents, this process was in itself viewed as an important memory as well as an acknowledgement of faith:

P2: they also allowed us to baptise him before we took off his support as well. They asked us if we wanted to have him baptised and we told them what faith, and they got a priest down from the chapel, so... they did all of that as well. But they did ask us, which was really nice. Because my husband is quite religious, so I think that helped him as well.

Interestingly, for the majority of parents, the description of this event was focused more on how it enabled them to involve others with their baby than on the significance of the rite or ritual itself. For example, some parents described involving the wider family during this ritual:

P13: I just thought it was important. And it is important. And our families were involved, so I guess that was another memory making thing. And clearly they made that happen in ICU, so that was a good thing.

For another parent, baptism provided an opportunity to engage in meaningful ritual with the staff who had cared for his son:

P17: they gave us the opportunity to have him baptised. And that was at 8-o'clock at night. They said "look, if you want to get him baptised, then we will organise a priest to come." So we had a father come at eight o'clock on a Wednesday or Thursday night. And we had four nurses as his god-parents. So there were four nurses that were very attached to him, and they put their hands up and said they would be honoured to do it. So we had a full baptism in his room as well. So that meant a lot to me, because I am a little bit religious.

While the spiritual aspects of blessings or baptisms were important to these families, these rituals also provided a means of involving others in the short life of their baby. Introducing one's baby to one's faith may provide comfort in itself, but introducing the baby as a member of a faith community and involving others in that process was also meaningful for parents.

6.5 IMPACT AND SIGNIFICANCE OF INVOLVING OTHERS

For some parents, having other people involved in their NICU stay was important as they felt that it helped others understand their loss:

P12: I believe it's really important for other family members to actually be a part of it. For them to (aside). I do think it's really important for other family to be around and to be a part of it. To actually get an understanding.

Similarly, another mother reflected:

P2: I think that the fact that our parents were able to be there when he passed away has really given us a good support network as well, because they understand. So the fact that the hospital allowed us to call them, and allowed them to be there, that's been really good for us. Because I can go to my mum, and be like "look, I'm remembering this and it's really upset me" and she's like "I know, I feel so bad, I was there too, I totally get that you are feeling that way."

For these parents, having others involved was seen as important as it provided family and friends with insight into their loss and increased their sense of support.

For other parents, having other people meet the baby provided important validation that an experience that felt ‘unreal’ did really happen, and that their baby did exist:

P8: it was definitely an incredibly dream-like time. Where... on our last night, while (baby) was still there in the hospital, we went over the road, just to get a pizza. And being out in the street, and you know, (wife), my wife's body had started to go back to normal... not normal... you know what I mean. And she wasn't breastfeeding, there was no pram, no baby with us, and she said "the whole pregnancy could have been a dream". If it weren't for having those people that we know had visited her, to validate that she did exist, it would have been a lot harder to convince ourselves that it had actually happened. Which sounds bizarre.

Finally, another mother commented that having others visit felt like a normal aspect of having a new baby. Being able to “show off” her son to others was important:

Interviewer: So was that helpful for you to have those people come in?

P18: Yeah I think so. Especially my best friend. Yeah definitely. I mean that's what you want to do with your baby in a normal situation, is to show them off. And even though it was under hard circumstances, that is still part of what you want to do. I mean I wish that everyone could have seen him to be honest, because he was so beautiful.

For the parents, involving others provided a form of validation that the baby did exist and validation that they were parents. Having loved-ones who had met and had shared memories of the baby also allowed parents to access social support more readily, as other

appreciated the scope of the parents' loss. Involving others helped parents to build additional evidence of their baby's existence that went beyond tangible items to shared experiences.

6.6 CONCLUSION

Parents in this study created evidence of their baby's existence in numerous ways. Firstly, having photographs was important as it helped to protect their memories of their baby over time, and to reflect on their baby's unique features, while also providing a way to share the baby with others. Similarly, having a range of mementos, and particularly having tangible items that the baby touched or wore, was considered helpful by parents. Such items provided aspects of the baby's size and physicality that were less evident in photographs, and were able to be touched and held in a literal sense. Mementos acted as evidence of the baby's existence and status as a 'real' baby. Finally, involving others allowed parents to develop shared experiences of the baby. These shared experiences provided a form of social confirmation that the baby existed, while providing social acknowledgement of the role of the parent and the scope of their loss.

Chapter 7: **Finding 3: Being Guided**

7.1 INTRODUCTION

The two key elements of memory-making described by participants in this study were “being a parent” and “creating evidence”. However, parents also spoke at length about the guidance they required to help them engage in parenting activities and to create or collect mementos during their baby’s time in NICU. Parents who received ample and active guidance spoke positively of their experience, while parents who needed guidance but did not receive it described missed opportunities to make memories with their baby. This chapter will explore the category “Being Guided” that was underpinned by two subcategories: “needing guidance” and “receiving guidance”.

7.2 NEEDING GUIDANCE

Parents experiencing the loss of a newborn found themselves in an unexpected and unfamiliar situation that was complicated by profound shock and grief. Parents explained that they needed staff to not only offer options, but also actively encourage them to engage in parenting activities with their baby, and to collect and create mementos. Several parents also spoke of health professionals who acted independently to ensure the family received photographs and other mementos.

7.2.1 Not knowing

Parents described not knowing what their options were with regard to memory-making, not knowing what was acceptable or appropriate in that situation, and not understanding the significance that memory-making activities and mementos would hold for them after the loss of their baby.

Not knowing options

Not only was the death of their baby profoundly distressing, but for the majority of parents, this was their first experience of death within their immediate family. This resulted in uncertainty for families and meant that they were reliant on guidance from staff.

P10: I think sometimes people tend to not realise that it's... we haven't gone through this before.

P13: we had never seen dead people before, we were young people.

Several parents commented that they had little understanding of their options with regard to memory-making, or indeed with the broader end-of-life care of their baby:

P1: I had no idea what would happen. Um, I had no idea that I could have photos. I had no idea that I could dress them, that I could bathe them, that I could do anything. I just... I didn't know anything. I just thought they'd be taken away and that would be it. I didn't even know if I could bury them, or if I could name them, or anything.

P9: what do you do... Because you have no clue. And you need to be guided by that then. Whether it's to make a memory or whatever else, you need that assistance and support

When asked what recommendations she would make to staff, another mother said:

P10: I think just offer as much as you can to parents. Even if they don't take it, just give them that option. Because often they are first time parents, or it's their first time in a NICU or something like that. And they don't know exactly what's going on. Whereas the nurses and doctors see it on a regular basis, and know what can be done and what can't be done. So I think just offer as much as you can.

Similarly, parents described needing to be told about opportunities for caregiving. For example, when asked what he would tell neonatal unit staff, one father responded:

P11: if there's an opportunity to hold them, make sure you let them know. If there's an opportunity to feed, or wash, or anything like that. Those are opportunities that the parent might like to do, but not know they can.

The alien environment of the NICU, combined with the medical fragility of the baby meant that parents were reliant on staff to facilitate opportunities for caregiving rather than feeling they could initiate care independently.

When asked whether bathing and dressing her baby was her idea or suggested by staff, one mother explained:

P18: it was a suggestion from the staff. To be honest I probably wouldn't have even thought of it I don't think. It was definitely them, they lead it. I don't think

they had any great big conversations with us about it, but it was just an offer and we went oh yeah.

These examples help to illustrate the need for staff to provide guidance to parents who might not be aware of opportunities to parent their baby and to collect or create mementos.

Most parents were too overwhelmed by their impending loss to consider options for memory-making. However, one father described going to the internet to understand the memory-making alternatives that might be available for him and his wife:

P8: I tried to Google “what do you do in the last few days of life” kind of thing (laughs). And I couldn’t find anything that was remotely helpful. So something like that could be helpful for parents in our situation. “Ok, now you’ve got this news that you know you are not taking your child home, here are some things that some families find helpful”.

The fact that parents are resorting to google to seek information about memory-making highlights the need for active guidance from health professionals.

Not knowing what is “normal”

In addition to not knowing what options were available, several parents chose to limit the time they spent with their baby after death, not knowing if it was “normal” to do so:

P13: I remember that they offered for her to stay with us for longer. And in hindsight there are lots of things I would like to have done. But we didn’t know what was normal, or... possible.

Another mother explained in more detail being constrained in her memory-making by her fears that the staff would think her unbalanced:

P1: And I suppose too, you.... The whole idea of taking photos of dead babies.... Sounds.... Before, I was just like “ick! Why would you want to touch a dead body, why would you want to do that?!” and I’m thinking that everybody else feels the same way, but I want to. And I want them with me and I wanted to do so many things, but I was scared they would think I was a freak, because I was touching dead babies. That sort of.... Yeah, that was my biggest regret.

This mother later added:

P1: now I know that that’s completely normal and that lots of people do it. And I didn’t know that I could do any of that. Because I’d never experienced the loss of a child, and I never knew anybody else who had experienced the loss of a child, until then.

Several other parents commented on being reluctant to take photos and being concerned that this was a morbid thing to do. For example:

P13: I think what you need to hear is... you need to know that other people have done it. Because at the time it seems like “why would I want to do that? My baby’s dead. Why would I want to have photos of her?” or that sort of thing. I think what you need to hear is “many bereaved parents find it helpful, or have found it comforting later on, if they’ve done this, or had this done”, that sort of thing. So obviously we did get guidance, and I don’t know if it was from the nurses or from the social worker, to take photos.

She added:

P3: I just think it needs to be said in a way that lets you know that other people have done it and it was helpful. Because at the time it just seems so wrong and so bizarre.

Parents in this study expressed a need for guidance around what was “normal” or socially acceptable around the loss of a child that for many would be considered taboo. Parents communicated a desire to be informed of memory-making options in a way that normalised otherwise potentially confronting options and that helped to explain why these might be valuable at a later stage in their bereavement.

Not knowing what would be important

Finally, several parents commented that they did not understand the significance that photographs or other mementos would have for them until well after their child’s death:

P9: You don't know that you should be taking a hundred photos, getting all these photos or getting these things, or getting something done for you, until afterwards. And you have missed out if you don't get that stuff done. And that's the biggest challenge for anyone that is bereaved... what's right to do in that situation. And not having a clue, because you don't expect this. Not knowing what you should do, or can do. So having information, but in a structured and simple way. Having someone to help guide you there is probably the most important aspect of the end-of-life situation.

Another mother described having photos taken by Heartfelt. While she was comfortable with this she explained that she didn't understand the significance they would hold for her months later:

P18: I probably didn't really grasp the full appreciation that I would have for it now.

These parents not only needed guidance about which mementos to create or collect, but also guidance around why these items might be important to them later in their grief trajectory.

7.2.2 Being overwhelmed

A number of parents commented that they were overwhelmed with the birth and imminent death of their baby and that they needed guidance as they were not in a good frame of mind to make decisions:

P14: You just can't function. You can't make decisions for yourself.

P9: Looking back and reflecting on it, you are not in the space to understand at times.

Another mother explained:

P3: I don't think I would have been in any state of mind to choose something.

Finally, this mother reflected:

P1: I understand parents are not in a position to think, or speak, or... you know, they're just not. Your brain doesn't work. You are just totally and utterly in shock, and you just sit there and go "ok." And people go "do you want this?" and you go "yep" "yep" "yep". And if it's not offered, you are not going to say yes.

These feelings of being overwhelmed increased parents' need for guidance as this mother explained:

P15: My main memory around that time was the fact that we were both so exhausted, both mentally and physically. You are only just managing to cope and exist, so any guidance or suggestions were brilliant.

Several parents explained in depth the feelings of shock, disorientation and uncertainty that they experienced around their child's birth, medical management, and death.

Parents frequently commented that they were not in a position to make meaningful decisions without guidance, especially where there was a degree of prognostic uncertainty and their focus was on the potential survival of the baby.

One mother explained that in addition to the shock of her baby's traumatic delivery and impending death, she was also dealing with being critically unwell herself, limiting her capacity to engage in memory-making or to make decisions:

P13: you are in shock. And in my case dealing with acute renal failure and you know, liver issues, and on transfusions and all sorts of things. I think time probably.... In cases where it's not just shock, but it is shock and a whole lot of other things, repeated offerings and a bit more time to take it on board would probably be a good thing.

Providing parents with as much time to make decisions as possible, and making repeated offers of memory-making interventions, was seen as important, especially in the context of maternal illness.

The unexpected nature of many of these babies' births and subsequent deaths contributed to parents' sense of being overwhelmed and impacted on their capacity to plan memory-making activities. For example, one mother explained:

P3: And really, looking back I don't know that we could have done it any differently. It was all such a rush. It wasn't planned, it wasn't something where you could say "ok, in the next three weeks we are going to have this baby who is not going to live, this is what we are going to do." It was just so instant. One day you've got this kicking, beating heart baby, and the next day you don't.

She later reflected:

P3: And certainly if you know ahead of time that your baby is not going to survive, I think you've got time to make those calls yourself, and say... you might go and get a little outfit, or you might make sure that you've got somebody prepared to take photos for you. I think you can be a little bit more involved when you know you've got time

Conversely, one mother who knew that one of her twins was unlikely to survive due to prenatal diagnosis described her experience quite differently:

P7: everything was well planned. You know, we'd met the neonatologist, everything was as well planned as you could, considering how everything was going. And that's important for me, because I like to be in control. And you can't be in control in these situations. (laughs). So it was a very well planned emergency caesarean (laughs).

She added:

P7: We'd had that opportunity. So really, the memory-making around (baby)'s passing actually started when we got the diagnosis. Because we were always told that there was only a 70% chance that they would both be born alive, and a 30% chance that you'd take one home.

Parents who experienced a sudden preterm delivery or whose babies experienced unexpected deaths were more likely to be overwhelmed and to have limited opportunities for memory-making, while advanced knowledge of the baby's poor

prognosis was helpful in allowing parents to plan and even commence memory-making prior to the baby's birth.

7.2.3 Needing simple written information

Several parents also commented that they were not given any written material about their memory-making options, or conversely, they were given overwhelming amounts of literature that they were unable to process until well after their child's death. For example, one mother recalled:

P15: You know we got quite a bit of the information after (baby) had died, which talked about making memories, but we weren't actually ready to read all that stuff, until a good three, if not six months later. We just weren't in the headspace. So the memories that other people created for us, are now the only memories that we have.

Another mother argued that a simple list of potential options should be provided to parents experiencing the loss of their baby:

P1: There are so many things that you can have done, that I just think it should be on the checklist. You know, and if they don't want them, well that's ok, put in in a box and you don't have to have them. But you can't change your mind! That's the problem. Once they're gone, they're gone. You can't go "oh actually, I think I might want..." it's too late. You've got to have... it's got to be done there and then.

She later added:

P1: It's just the things you don't know you can do. There should be a book. Like "I'm sorry your child is going to die, but you've got to make a lifetime of memories right here and right now." So every single option should be there. Every single one.

One father also described the need for clear and simple information:

P9: Simple information, not 25 pages of crap. But some clear information about what.... It could be as simple as a fact sheet, about things that you could do that may support you after your loss.

These parents felt that the unexpected and overwhelming nature of their loss made reading and understanding large volumes of written material difficult. Having simple, brief written information outlining the possible memory-making options would have been valuable for these parents.

7.2.4 Needing reassurance

Finally, some parents expressed concerns about hurting the baby or fears that they would hasten the baby's death by handling them. One couple explained that reassurance from staff would have encouraged them to hold their son more frequently:

P16: it took a fair bit of effort to take him out of the incubator as well.

P15: But if someone had been standing there, telling us "it's better, it's good, he needs you. Can you see how he's responding?" that certainly would have made it easier to do.

This mother later reflected:

P15: I think the biggest thing for me is that we were so scared of touching him because he just looked so sick. Hearing those awful noises that the machine made. And every time we did something the machine would pause or something. So I think reassurance from the nurse would have been a very good thing at that point in time. Just saying “no, it’s ok. It’s supposed to do that. You are not hurting him”. I think that would have been the only thing that I would suggest. Because like I said, we didn’t.... I didn’t want to take him out of the incubator, because it just seemed to stress him so much, but...

While parents needed guidance around the collection and creation of mementos, they also needed reassurance that far from being harmful, having contact with their baby and contributing to their care was valuable and important.

7.3 RECEIVING GUIDANCE

Parents who received active guidance were typically more positive about the bereavement support they received. For example, one mother recalled the guidance provided by the unit social worker:

P1: we were lucky enough, we had a fantastic social worker who was on in the NICU. And she was really really good. She sort of went through and explained everything that would happen. Um, and sort of went through with us what we could do and what we couldn’t do. Yeah, we had no idea what we could do.

Similarly, one mother explained:

P10: Just having the nurses going “if you want to do this”, or “why don’t you help me do this”... it was good because we were like “we don’t know what to do, we’ve never been in the NICU before, or anything like that”. So I think it was really good to have those suggestions.

Being given anticipatory guidance about what to expect, as well as more directive guidance about opportunities for caregiving and for contact with the baby was helpful for these parents.

Another mother admitted to being overwhelmed by the options provided but being glad in retrospect for the opportunities she had for memory-making:

P4: We were given quite a lot of options... if anything, possibly too many. Because you know, you’re just... you don’t ever even think about being in that position, let alone some of the decisions to be made. But you know, they have to be made. But they were really.... Everybody was really accommodating. And they were things that in hindsight, we were really glad they were offered. Because we wouldn’t have known what to ask for.

While being presented with an array of options was potentially overwhelming at times, all of the parents in this study were grateful for opportunities to parent their babies and were pleased to have mementos that were collected or created in NICU.

Some parents expressed a need to have options offered on multiple occasions. For example, this mother described being dazed and overwhelmed after delivering her son unexpectedly at 24 weeks, and needing time to process the options available:

P18: I think it is important to be a bit, not persistent, but to mention it more often not just the once.

Another couple explained:

P15: you can't know what the person is thinking, all you can do is give them the options, over and over and over and over again.

P16: And explain why

P15: and just present it out there, and say look "this is what I suggest you do" ... or not even that "we can do this, you can do this" and then just keep offering it until the person either takes that idea or tells you to go away nicely (laughs).

Several parents commented that because they were overwhelmed and distressed, information needed to be provided repeatedly, and this included discussions around options for memory-making.

Another parent explained that the guidance they were given was made to sound like a series of choices but in retrospect acted more as a series of suggestions:

P6: I guess in hindsight they probably weren't choices. They were sort of telling us what we needed to do. Because we didn't know what we needed to do. But they were presented to us as choices at the time. In hindsight, how they deal with it is just amazing. We were just in a blur and didn't know what to do. So without telling us how to look after our baby and what we needed to do for our baby, they were doing it. Do you know what I mean?

Parents in this study were typically satisfied with their bereavement care when they were not only provided with options or suggestions, but were actively encouraged to engage in memory-making, highlighting the importance of guidance for this cohort of bereaved parents.

Interestingly, several participants used stronger language to describe the encouragement given by nurses to engage in memory-making activities, such as being “pushed” or being “made” to engage in acts of parenting or in the collection of mementos. For example, one couple explained:

P15: The nurses in there were excellent in that they really strongly encouraged us.

They didn't force, but they continued to... I don't even know how you explain it.

They continued to politely push and encourage us to do things that we....

P16: Cherished later on.

P15: Yeah, that's it.

Similarly, one mother commented:

P6: luckily the nurse had obviously done this plenty of times before and she was like “you really need to do it”. She sort of had to give us that little bit of a push I guess. She was incredible. She gently pushed us in the right direction for everything. Which at the time, we were sort of like “no, we don't want to do that, that's just.... It would be annoying, or it's not what we need right now. But after he was gone, that's all we had.

Another mother expresses gratitude for the nurse who “made” her hold her son before he died:

P12: I didn't want to nurse him. I thought it would be no good. But I will be forever grateful to the nurse that made me nurse him. She literally pulled him out and said "no, you are going to nurse him". And I will be forever grateful for that.

Finally, for another mother, more active guidance would have been helpful:

P14: Sometimes you need to be gently pushed in the right direction

Parents used the words “gently” or “politely” as modifiers when explaining how they were “pushed” or “strongly encouraged” to engage in memory-making and several stated that they were not “forced”; rather parents seemed to be describing a persistent, encouraging approach that steered them towards memory-making activities. None of the parents in this study described episodes of feeling uncomfortable or distressed by this form of guidance. For these parents being “pushed” to engage in memory-making activities, or being “made” to undertake key acts of parenting was appreciated, especially after the initial shock of the loss had subsided and they were left with memories and mementos that they may not have considered as being important until after their loss.

In addition to being guided to participate in memory-making activities, several parents explained that the health care team had provided some mementos without discussing this with the parents:

P3: I don't remember anybody saying "would you like this?" I just know that the box appeared, and the clothes were there. They just...they just seemed to know what to do. And I didn't have to ask for the hand or the footprints to be done. They

were just done. They just... everything seemed to just appear. She adds: The memory-making is the bit that we rely on for the midwives to provide for us.

P2: they didn't tell us they were doing a memory box, so it was quite a surprise. To not expect anything at all and then to get this lovely box of mementos... so that was nice.

P9: The memory box was... we just got given it. And we didn't know what it was about.

Most parents expressed gratitude toward the staff who had collected or created mementos without prompting. For example, the mother from one couple said:

P15: they just created experiences for us, which was really good. Like on day we came in and one of the nurses had done the foot prints on a card. So what she'd done was basically just gotten a coloured card, done feet prints of (baby) on one side, and then on the other side had put a photo of him, and then laminated it together. So it was just this...it's still on our fridge. Seven and a half years later and we've still got it on our fridge. And it's just little things like that

This couple later added:

P15: we didn't know what memories to create. We weren't in the right headspace to be even thinking about memories or mementos, or anything like that. So having somebody who did that for us is so invaluable. Because at the time, you are just doing anything you can to get through. You don't really give a shit about photos because you can't even begin to think about what is going to happen in 24hours time, let alone six months later.

P16: and without that we would have had a couple of photos and a couple of small things, and that's it. Whereas now at least we have something.

Similarly, one father explained:

P9: You need to be guided around this time. Like if (nurse) hadn't have done the hand and foot prints, we would have nothing for him. She just got this book and did it. And we had no idea. I was actually going to stop her and go why are you painting my son's feet! (laughs)

Finally, this mother explained the need for staff to engage in memory-making on parents' behalf:

P13: you're not really absorbing things. And I think sometimes you just need it to be done for you, and then just offered to you.

For these parents, having someone create or collect mementos without prompting was seen as valuable, giving them more mementos than they might otherwise have had after the death of their child.

Similarly, one mother explained that she had refused to hold her baby because she was afraid that handling him would hasten his death. She described a nurse removing her baby from the isolette and handing him over, despite her misgivings:

P12: if that baby is definitely going to die, and the parents don't want to because of that fear, then I do believe do it. The nurses should just do it. Just do it. I know it sounds bad, but it was done to me, and just do it. It's so important, because you will live with regret if you don't. It's the unknown. Living with that unknown, that regret. It's very important.

For this mother, having the choice taken out of her hands and simply having her baby handed to her was viewed as a supportive and helpful gesture, even though she had previously refused to hold her son.

Conversely, a few parents identified that they would have liked to have been more involved with memory-making, and in particular, in the process of collecting mementos. For example, one mother reflected:

P2: We didn't really have to organise too much in ourselves, but they also didn't really ask us if we would like to take part in anything.

She later expanded on this:

P2: like if the parents themselves would like to do the hand and foot prints. And I know I would have loved to have been able to be part doing his hand and foot prints. And you know, the hospital did a great job, but it would have been a really nice experience for me to be able to do that. Because I'm never going to be able to get his hand and footprints. And I think that's the view that the hospital really needs to take, that the parents aren't ever going to get to do this. So, anything that the parents can be involved in, even if it's something small, like, "do you want to take a lock of her hair and we'll put it in a nice box for you".

For this mother, the act of creating or collecting mementos was an opportunity for interaction with her baby that in itself would have acted as a positive memory.

Finally, there were three instances identified in the data where parents were unhappy with mementos collected without their knowledge. One parent was unhappy that a lock of hair had been collected without her consent (see page 167), another parent

was distressed to be given photos of her baby being bathed (see page 124), while one couple was distressed with photos taken of their baby in a burial gown. While parents in this study were generally grateful for the mementos or photographs provided by staff, there were some situations where these items resulted in distress.

7.3.1 Accepting or refusing options

While parents in this study all engaged in some parenting activities and all had mementos and photographs as evidence of their baby's life, parents at times described refusing specific memory-making activities. As described in Chapter 5, several parents declined offers to have their baby brought to them from the mortuary or to take their baby home from the hospital prior to their burial or cremation. While parents described their refusal of these options because they felt they would be too distressing, all parents reported being comfortable with such options being offered.

A few parents in this study commented that they were more willing to accept guidance offered by staff whom they had developed a rapport with over time, and who had shown a personal interest in their baby:

P16: the other thing that comes through is the fact that you don't mind... whatever opinions or suggestions they give you, it's the fact that they were showing that they quite obviously cared about (baby). That's the thing. So you take that feedback on board. You know... what whatever advice or suggestions they give you, it's the care that they show, you know their heart's in the right place, so you appreciate that... that input.

Where parents felt that staff were making suggestions from a place of caring, they were more willing to accept the options that were offered by staff.

Interestingly a number of parents commented that while they refused some of the options that were offered by staff, they recognised that each parents' needs would be different:

P12: I don't know that there's always going to be a right way or a wrong way. I think everybody is different

P4: I realise that really to some extent they're in a no-win situation, because it's such an awful experience, that everybody's going to want something different

P9: everyone is going to have very different ideas about what sort of memories that person wants.

This insight that others might appreciate options that they themselves had refused meant that these parents were not offended when such options were presented, even when they chose not to accept them.

7.3.2 Inadequate guidance

Where parents felt they lacked active guidance, they often experienced regret around missed opportunities for memory-making. For example, one father recalled:

P11: we didn't realise that we were able to hold him before his surgery. So we missed out on that.

Another father described discovering parenting activities by accident rather than being encouraged to be involved:

P8: most things I felt like we.... It was kind of up to us. So for example, the nappy change thing, I just happened to be there when they were changing the nappy, and said "ooh, can I do that?". And then told my wife. I said "how often do you do this?" "oh, every six hours" or whatever it is, and I'm like "Great, ok, what time is the next one, we will make sure we are here." So that was something that the hospital could have actually prompted us or let us know, and asked us whether we would like to take part.

Similarly, this father described a lack of guidance around skin-to-skin kangaroo care until his daughter's final days:

P8: With the cuddles, there were two different types of positions, there was just the (mimes cradle hold) head in my armpit kind of cuddle, and then there was the (mimes holding baby to chest) kangaroo cuddles. And we didn't know about the kangaroo cuddles until the last day or two, and I guess maybe we wish we could have had those type of cuddles sooner, because they are a bit more close.

While this father spoke highly of the care he and his family received, opportunities for memory-making that were lost as a result of insufficient guidance were still a source of regret.

Another father identified that being guided through memory-making is perhaps one of the most important aspects of end-of-life care:

P9: Having someone to help guide you there is probably the most important aspect of the end-of-life situation. And it's not taboo to spend time with them, or to take photos, or to do things. Because they are some of the most important things for

you after the fact. When you are six months down the track, and you've actually got a little bit of sanity, or three weeks down the track, and you go... I haven't got anything. Or even a year down the track. And it's like well, that's when you start realising what you've missed out on.

This reinforces the concept that parents may not understand the potential impact of memory-making activities until well after the child's death, and that guidance is required to ensure parents are not left with any regrets.

Finally, one mother recounted being "stuck in a room" while her baby was washed and dressed, without being offered an opportunity to participate. She described the need for nurses to encourage parents to be involved in the care of their baby:

P14: I think just a bit of encouragement. Just gentle encouragement. Not forced to do something, but to just sit in that room on your own and not know what was going on with him. That was really difficult.

Although this mother's loss occurred 17 years ago, the missed opportunity to be involved in the final care of her son still caused distress.

This importance of guidance around memory-making for families can most clearly be seen where guidance was lacking. Parents who were not guided effectively described missed opportunities to engage with and care for their child, as well as opportunities to collect or create mementos. Parents who did not receive adequate guidance expressed regrets that might easily have been avoided through effective and empathetic communication.

7.3.3 Impact and significance of Being Guided

Being guided to participate in memory-making activities, and having others creating or collecting mementos, impacted powerfully on parents' perception of the quality of care. For example, one father reflected:

P11: they were really good at the hospital. And I must say that is one think I was completely impressed by, at the hospital was that they tried to make sure that we had as many memories as possible with him as we could.

Another mother recalled lacking the confidence to ask to spend time with her babies post-mortem:

P1: she came in and sort of all... I wanted to do all of those things, but I didn't know whether I could. And I was too scared to ask. So yeah, she came in and she was brilliant. Yeah, she was really, really good.

Finally, one father explained:

P16: I can't stress enough that the midwives in there were brilliant. They weren't too forceful, but they gave us the options and the information

Parents who felt that they were given active guidance were positive about their experience of care in the neonatal unit. In particular, parents who were supported to have contact with their baby, and who were involved in caregiving, had more opportunities to form positive memories with their baby. Similarly, parents who were encouraged to collect and create mementos, or who had these provided by staff were grateful to have these items and were more broadly positive about the quality of care.

7.4 CONCLUSION

Parents valued opportunities to spend time with their baby and to provide care for them as a way to step into the parenting role, and as a way of forming meaningful memories with their baby. Tangible mementos and photographs were also important to parents as a way to validate their baby's existence. Sharing the baby by involving others and sharing mementos helped to ensure the baby's memory would endure, and the role of the parents was acknowledged, both by others and by the parents themselves. Guidance around "being and parent" and "creating evidence" was critical for parents who were in an unexpected situation and often overwhelmed with uncertainty and grief. Parents who received inadequate guidance had the potential to miss opportunities for memory-making and this sometimes resulted in long-term regrets. Conversely, parents who were actively guided to create and collect mementos, and to spend time with their baby and to parent them, were deeply grateful to staff, even when they chose not to accept some of these activities or items.

The following chapter will explore the substantive grounded theory developed from the three key concerns of parents: "being a parent", "creating evidence" and "being guided" that underpin the psychosocial process of memory-making in neonatal end-of-life care.

Chapter 8: Discussion

8.1 INTRODUCTION

Memory-making in the context of neonatal end-of-life care is complex and imbued with multiple meanings. This study used a grounded theory approach to explore the significance and impact of memory-making interventions for parents experiencing the death of their baby in the neonatal unit. For the parents in this study, the three key elements of memory-making that emerged were: 'Being a Parent', 'Creating Evidence' and 'Being Guided'. In the following chapter, each of these three elements of memory-making will be examined in detail, and the findings of the current study will be compared and contrasted with the existing literature surrounding perinatal bereavement care.

8.2 POSITIONING THE STUDY WITHIN THE LITERATURE

As described in Chapter Two, there has been limited research that has focused on memory-making interventions in the specific context of neonatal end-of-life care. However, studies that explored parents' perceptions of end-of-life care in perinatal or paediatric contexts frequently revealed memory-making as a primary concern for bereaved parents. The following section will position the findings of the current study in the context of this broader literature.

8.3 BEING A PARENT

The category ‘being a parent’ captures the need expressed by participants in the current study to spend time with their baby, to have physical contact with them, and to engage in caregiving and provide comfort. Parents who were able to be with their baby, hold them, and care for them, described this as the most meaningful aspect of their memory-making experience. This observation is in line with findings from the broader perinatal bereavement literature. For example, Koopman et al. (2013) conducted a Cochrane Review of perinatal bereavement care, and reported that “For many parents, it is the experience of parenting, not mementos, which is the most valuable in the creation of a bond” (p. 5). It appears that for bereaved parents, both in the current study and in the perinatal bereavement literature, ‘being a parent’ is the most significant element of memory-making. When ‘being a parent’ is supported, facilitated or encouraged by staff, participants experience affirmation of their role as parents to their baby.

For the parents in the current study, ‘Being a parent’ was characterised by three key themes. Firstly, parents described the need for contact with their baby. This included spending time with the baby, before and sometimes after death, and having physical contact with the baby through touching and holding. Secondly, participants described engaging with their baby through talking, singing, or reading to the baby, as a way of parenting their baby when physical contact was not possible. Finally, parents emphasised the importance of participating in caregiving activities, such as bathing, dressing, or changing nappies. The following section will critically examine the findings which underpin ‘being a parent’, and position these findings within the perinatal palliative care and bereavement literature.

8.3.1 Contact with the baby

Research regarding contact between parents and their infant in perinatal end-of-life care has focused primarily on outcomes in parents experiencing stillbirth, leading to mixed results. While the majority of parents across studies seem to desire contact with their stillborn baby, the research suggests that such contact may increase the risk for negative psychological outcomes, at least during subsequent pregnancies (Hughes et al. 2002). However, a systematic review involving 23 research articles found that only the two papers by Hughes et al. demonstrated this association between holding the stillborn baby and increased psychological morbidity. The other quantitative papers in the review reported either no association, or an increased incidence of psychological morbidity in parents who had *not* had contact with their babies (Kingdon, Givens, O'Donnell and Turner, 2015). Finally, Radestad et al. (2009) found that holding infants who were stillborn close to term was associated with positive psychological outcomes, while this relationship was less apparent when the infant was stillborn between 28 and 37 weeks gestation. These complex and sometimes contradictory findings have resulted in an emphasis on parental choice in the perinatal palliative care guidelines; while parents should be offered the choice of seeing and holding their baby, guidelines frequently stress that parents should not be steered toward contact with their baby (BAPM, 2010; PSANZ, 2009).

Conversely, opportunities to see and hold the baby have been identified as critical in the context of neonatal end-of-life care (Abraham & Hendriks, 2017; Baughcum et al., 2017; Lasker & Toedter, 1994; McGuinness, 2015). While the evidence supporting contact between parents and their stillborn infants remains somewhat mixed, this does not hold

true for parents of live-born infants, demonstrating the dangers inherent in conflating parents experiencing stillbirth with parents experiencing the death of a newborn under the heading of 'perinatal loss'.

Indeed, all of the parents of live-born infants in the current study expressed a deep need for physical contact with their babies. All of the parents held or touched their babies while they were alive, and were present at the time of their baby's death. In most cases, either the participant, or their partner, were holding the baby as they died.

As described in chapter two, findings from previous studies suggest that while the experience of holding their dying baby can be intensely challenging for parents, this experience may also be incredibly meaningful. Abraham and Hendriks (2017) report that the parents of dying newborns in their study wanted to hold their baby and "felt a profound need to fulfill this parental role and to give some warmth and support to their dying baby" (p.2107). Parents in their study perceived holding their baby as a means of providing love and comfort to the dying child, and considered this to be a fundamental element of the parenting role. This mirrors the findings of the current study; participants described a need for support and reassurance to hold their baby during the final moments of life, however this experience was perceived as an important aspect of the parenting role.

While participants in the current study identified physical contact with their baby while they were alive and during their final moments as critical, these parents also described a number of barriers to experiencing contact with their baby. Firstly, the environment of the NICU posed a significant barrier to contact. Parents explained that isolette walls or invasive lines and monitors limited physical contact with their baby and

made the parent wary of touching them. Simultaneously, tapes and tubes on the infant's face impacted on parents' visual contact with their baby.

There is a significant body of literature exploring the relationship between the NICU environment, and parents' comfort and capacity to see, hold and engage with their baby (Abraham & Hendriks, 2017; Currie et al., 2016; Gale & Franck, 1998). For example, Gale and Franck (1998) explain that in the NICU environment, "Parents may feel as if they are strangers; are fearful of touching anything, including the baby; and may also feel incompetent in providing care for their newborn" (p.64). The authors add that parents "may feel that their parental role cannot begin until after the baby is discharged from the unit" (p.64). While 'being a parent' was a significant aspect of memory-making for parents in the current study, it appears that the NICU environment may impact negatively on parents' contact with their baby and as such, may act as a barrier to 'being a parent'.

From a practical perspective, several mothers in the current study also experienced delayed or restricted contact with their baby due to their own physical condition after delivery. Mothers who had undergone emergency caesarean delivery, or whose preterm labour was occasioned by physical illness, were more likely to have delays in seeing their baby, or to be physically unable to touch or hold their baby in the hours after the birth. This experience of delayed contact was not clearly evident in the perinatal bereavement literature, although a delay in contact between mother and baby is a common occurrence in the context of cesarean deliveries (Collard, Diallo, Habinsky, Hantschell & Vezeau, 2009) as well as for pre-term infants receiving active treatment in the NICU setting (Treherne, Feeley, Charbonneau & Axelin, 2017).

Although several mothers in the current study experienced delayed contact with their babies, there were also instances where mothers were supported to be with their baby soon after delivery. Mothers who perceived that efforts had been made to reunite them with their baby were deeply appreciative, and this had a positive impact on their experience of memory-making, and of end-of-life care more broadly. While separation may be unavoidable due to the care needs of the infant or the mother, consideration needs to be given to reuniting parents with their infant as soon as it is safe to do so, especially in situations where the infant is delivered extremely preterm or where the prognosis is known to be poor. Further research around delayed parent-infant contact in the context of neonatal end-of-life care may help to support improved care for parents.

Finally, parents in the current study frequently described the physical condition of the infant as a barrier to contact. Participants were afraid that handling their baby would cause pain or deterioration. Indeed, contact was frequently restricted until a decision had been made to limit treatment, or when it was understood that the baby would likely die despite intensive therapy. It was often only after parents were told that curative treatment would be futile that contact with the baby was facilitated.

This pattern of restricted contact until the limitation or withdrawal of treatment is in keeping with previous studies of end-of-life care in neonatal units (Armentrout, 2007; Currie et al., 2016). For instance, Armentrout (2007) found that parents often experienced restricted contact with their baby until the decision to withdraw life support was made. She reported that the decision to withdraw life sustaining treatment:

...actually provided them with an opportunity to spend time with their infant as a member of their family. For most, it was the only time they were able to hold and talk to their infant like a 'normal baby without all the tubes and wires.' (p. e7).

Such findings highlight the importance of prioritising parents' contact with their baby and providing guidance for parents around touching and holding the dying infant. Facilitating contact between parents and their baby is critical in enabling individuals to parent their baby and is fundamental to affirming the role of the parent.

For parents in this study, skin-to-skin contact with their dying baby was identified as an especially valuable form of contact. Parents who had the experience of holding their dying baby skin-to-skin reflected on this as an incredibly meaningful experience, while several parents who did not hold their baby skin-to-skin expressed considerable regret. The significance of skin-to-skin contact was explored with parents in the NICU setting, in a meta-synthesis by Anderzen-Carlsson et al. (2014). The authors reported that skin-to-skin care was experienced as both restorative and challenging for parents. However, positive experiences of skin-to-skin contact were found to promote the development of parents' self-esteem and enabled them to step into their role as parents. This desire for skin-to-skin contact has also been identified in the perinatal bereavement literature (Nordlund et al., 2012). While any form of contact between parent and baby is potentially valuable, the tactile memory of holding a baby against one's skin was treasured by parents, both in the current study and by participants in existing perinatal research.

Contact with the baby while they were alive, and as they were dying, was an important aspect of memory-making for all of the parents in the current study. However, contact with the baby after death generated mixed feelings for a number of parents. For instance, some parents described deliberately limiting contact with their baby after they had died. These parents described a desire to retain the image of their baby as they had been in life, rather than having those memories replaced or tainted by the image of their baby once post-mortem changes had occurred.

In contrast, spending time with the baby after they had died, and touching or holding them, was important to the majority of parents. This time spent with the baby after they had died was described in detail by parents whose babies lives had been very brief, or who experienced restricted contact with their baby while they were alive. It is possible that parents who interacted more with their infant during life placed less emphasis on spending time with their bodies after death, as their need to create memories with the infant had been more fully met. This temporal aspect of memory-making is something that has not been explored in the literature and represents a unique finding from this study which warrants further research.

8.3.2 Engaging with the baby

In addition to spending time with their baby and touching or holding them, parents in this study spoke of opportunities to engage with their baby as meaningful. As described in chapter five, parents used a range of strategies to engage with their baby, including talking, reading or singing to the baby. In particular, the need to study the baby closely and to absorb the intricate details of their appearance for later recollection was described as important by several mothers.

Strategies for engaging with unwell or dying newborns, such as singing, talking or reading to the baby and studying their features, have also been described in the perinatal bereavement literature (Abraham & Hendricks, 2016; Baughcum et al., 2017; Cacciatore & Flint, 2012). For example, Baughcum et al. (2017) found that in situations where the infant was too fragile to be held or touched, parents spent time studying the baby's appearance or talking to them as an alternative way of "doing something" for their baby. The authors explain that parents felt the need to engage with their baby in any way possible; while physical contact was ideal, other forms of engagement were also important to parents.

Similarly, for participants in the current study, engaging with the baby was an important element of being a parent. When parents were unable to have physical contact with their baby, they described an overwhelming need to do *something* for their baby. Parents described feeling grateful when nurses acknowledged their need to engage with their baby, and made suggestions such as talking or reading to the baby. Engaging with the baby allowed parents to intentionally develop memories with their baby, and acted to affirm their role as the parents of *this* baby.

8.3.3 Caregiving

Caregiving emerged as perhaps the most significant aspect of "Being a Parent" for participants in this study. Opportunities to engage in typical caregiving tasks, such as bathing the baby, changing nappies or dressing the baby were described as incredibly meaningful by participants. Conversely, lost opportunities for caregiving were profoundly distressing to participants and impacted significantly on their identity as a parent.

As described in Chapter Three, multiple studies have identified parental caregiving as an essential aspect of neonatal bereavement care (Abraham & Hendriks, 2017; Baughcum et al., 2017; Brosig et al., 2007; Currie et al., 2016; Lathrop & VandeVusse, 2011; Lemmer et al., 1991). In particular, research suggests that memories of engaging in ‘normal’ infant care were especially comforting for bereaved parents (Meert et al., 2005).

While multiple studies describe *what* parents found important or helpful in perinatal end-of-life care, less attention has been paid in the literature to *why* these elements of memory-making were significant to bereaved parents. When asked about the impact and significance that memory-making held for them, participants in the current study described such experiences as helping them to *become* parents to their baby. This concept of stepping into the parenting role through caregiving was also reported by Currie et al. (2016). The authors found that ‘Being a parent in the NICU’ was a core theme of neonatally bereaved parents’ stories. Currie et al. explained that “maintaining the role of the parent was a priority during the infant's life, surrounding EOL (end-of-life) care, and at the time of death.” (p. 481). It appears that for neonatally bereaved parents, both in the current study and in the existing literature, engaging in caregiving is a fundamental element of memory-making in neonatal end-of-life care and allows parents to integrate parenthood into their own identity.

While engaging in caregiving supported participants in the current study to develop a sense of parenting identity, participants who experienced limited opportunities for caregiving expressed regret. More specifically, several parents in the current study expressed a wish that they had been able to engage in more ‘normal’ parenting activities with their babies. These findings parallel those of Armentrout (2007) who conducted a

grounded theory study involving parents who had experienced the death of an infant following withdrawal of life-sustaining treatment. She reports that in retrospect, parents wished they had engaged in more parenting activities with their babies, as these were a treasured source of memories.

Any opportunity to provide care to the infant is potentially valuable to bereaved parents. However, specific caregiving behaviours were identified as especially meaningful by participants in this study. Memories such as bathing their baby, and dressing or swaddling them stood out to parents as particularly poignant. These activities are also frequently recommended throughout the perinatal bereavement literature (Gold et al., 2007; Harvey et al., 2008), and in perinatal or neonatal palliative care guidelines (ACNN 2010; BAPM, 2010; DHS, 2017; PSANZ 2018). However, as with other aspects of memory-making, limited attention has been paid in the literature to explaining why these experiences might be particularly powerful. The findings of the current study indicate that as everyday parenting activities, engaging in caregiving with the dying infant enables individuals to embody the parenting role, which in turn affirms their identity as parents.

Interestingly, several mothers also spoke in detail about their desire to choose their baby's clothing. Being able to select an outfit, rather than simply being given clothes, was an important way for these mothers to parent their babies. Some parents were given a choice of items from those available on the unit, while others described shopping for size-appropriate items, or bringing items from home that had been purchased or made specifically for this baby. All of the parents who were involved in choosing their baby's clothing reflected on this as a positive memory they associated with parenting their baby, while parents who were not supported to choose clothing described this with regret.

The significance of selecting clothing as an act of parenting is a new finding with this study. One guideline was located that encouraged nurses to use clothing provided by the parents (ACNN, 2010). However, no studies or guidelines around perinatal bereavement were found that directed nurses to allow parents to choose from the clothing available on the unit, or to encourage parents to bring in their own items from home.

The ability to choose clothing for the infant may be important to parents for several reasons. Firstly, clothing is a way of expressing identity. As described by Twigg (2009) "Identity and dress are intimately linked. Clothes display, express and shape identity, imbuing it with a directly material reality" (p.1). In this sense, choosing clothing may represent one way that parents can assert a unique identity for their lost child.

Secondly, choosing clothing is a typical aspect of parenting a newborn and engaging in such activities may act to affirm parenthood. The website of a parent bereavement support group captures this notion perfectly, using quotes from bereaved parents. One such quote reads: "Midwives shouldn't choose the clothes, parents should, because you want to do something for your baby, and there is very little that you can do as parents". Another states: "The only decision you can get to make is what your children wear – you should be allowed to make that decision" (Red Nose, 2016). Being able to act on behalf of the infant and to make choices for them is both a right and a rite of parenthood and this may be even more significant in situations in which so few acts of parenting may be possible.

For parents in the current study, being able to provide care to their baby helped to affirm participants' identities as parents, while simultaneously building positive memories with their babies. Activities that approximated typical newborn care were valued. In addition, activities that allowed celebration of the infant's uniqueness and affirmation of their personhood, such as the selection of clothing and dressing of the body, were important to parents in this study. These aspects of memory-making have not been thoroughly explored in the literature and warrant further attention.

'Being a parent' was an important element of memory-making for all of the participants in the current study. Opportunities to touch and hold the baby, to engage with them and to provide care all help to affirm the reality of the infant as a unique individual to be loved and mourned, and in doing so, may validate parents' feelings of loss and grief. These same activities help to affirm participants' sense of parenthood.

8.4 CREATING EVIDENCE

Parents in this study created evidence of their baby's existence through collecting or creating mementos, taking photographs, and involving friends and family in the baby's life and death. As described in Chapter Six, parents in the current study collected or created a range of items that acted as mementos of their baby's brief life. Each of the participants also had photographs taken during the baby's life, or after their death. Parents in this study described the importance of these items, not only as aides to memory, but also as evidence that their baby was a real person worthy of being remembered and mourned.

The use of mementos to help to affirm or validate the parents' loss has previously been identified in the literature. For example, Lundqvist et al. (2003) explain that the collection or creation of mementos help to "validate the parents' sense of loss, help them relive the experience and attach meaning to the loss" (p.197). Narratives of women in the context of perinatal hospice also revealed the importance of tangible mementos as a way to prove to oneself that the pregnancy and the baby were real (Lathrop & VandeVusse, 2011a). The authors explain that "Tangible mementoes were another way that mothers sought to affirm their babies' reality" (p. 260). The current study contributes to the evidence surrounding photographs and other mementos as a means of recognising and honouring the life of the baby, and the loss of the parents, as real and important.

8.4.1 Bereavement Photography

As described in Chapter Six, all of the parents in the current study had photographs of their baby, and all were grateful that they had taken, or were given these photos. Photographs which captured moments of caring between parent and child, or which showed the baby in the context of their family, were especially important to the bereaved parents in this study. In one particularly poignant example, a mother described photos taken by staff when she and her husband were holding their twins. She explained that she "never would have thought" to photograph this moment, as her focus was on holding her babies, however the nurse waited until both parents were cuddling their twins and took photos without interrupting that moment. These photographs now represent the only time that this mother's "whole family" were together in a physical sense. Similar themes were apparent in the literature surrounding bereavement photography. While any photos of the baby are potentially important to parents, those

which capture the living baby with their family have been identified as especially meaningful (Blood & Cacciatore, 2014a).

Parents generally appreciated photographs taken where their baby was alive, while images taken by staff after the baby had died were met with mixed emotions. Some parents appreciated these photos, as they were often the only images which showed the features of the baby clearly. Conversely, receiving images of the baby which were clearly taken post-mortem was distressing to some parents. Sensitivity was important when staff elected to take photographs after the baby had died, especially once post-mortem physical changes became apparent.

For parents in this study, bereavement photography held deep significance as an element of memory-making in neonatal end-of-life care. However, photographs were more than simply a record of the baby's appearance. Rather, photographs provided important evidence that the baby had existed and was a 'real' person. Parents were frequently "in a daze" or completely overwhelmed at the birth and death of their baby, resulting in a feeling of unreality around the death. Having photographs of the baby acted support recall, but more importantly, these photographs helped to affirm the reality of the baby's life and death for the parents.

These findings are well aligned with the research described in Chapter Two, which revealed that bereavement photography served several important purposes for perinatally bereaved parents. These include the construction of an identity for the baby, as well as confirmation of the role of the parent. For example, Godel (2007) argues that:

Through these images, parents appear to be creating a social identity for their babies, and integrating the stillborn baby into the family. In doing so, they are also establishing their own roles as mother and father, especially if the baby was their first born. (Godel, p.258).

Although this research was conducted with parents experiencing stillbirth rather than neonatal death, it is likely that photographs of live-born infants serve a similar purpose; allowing for the construction of identity both for the baby and for the parent.

Indeed, this finding in the bereavement research might explain why photographs which captured moments of caregiving were so deeply appreciated by bereaved parents in the current study. For example, Martel and Ives-Baine (2014) conducted a phenomenological study involving parents who had experienced the death of a newborn. The authors found that when parents were asked to identify their favourite bereavement photographs:

the value of these images was the embodied interaction they captured, as another commonality noted amongst the “favorite” images was that they tended to be taken around moments of the family together with the newborn, performing gestures or actions that could be identified as “parenting”. (p. 320)

For individuals who had such a brief time to parent their baby, any evidence of this relationship was treasured.

In addition to helping participants to construct an identity for the baby and reconstruct their own identities as parents, photographs also provided crucial evidence of the baby’s existence for others, and provided a mechanism for the social validation of

parenthood. Research surrounding bereavement photography in the context of stillbirth reveals a similar theme. As described by Cacciatore (2010) “Bereaved mothers desired both an internal and an external recognition and valuing of the baby’s identity” (p.141). She made a compelling argument that interventions such as photographing the baby can be helpful in meeting this need.

By providing a means of social acknowledgement of the infant as a ‘real’ person, and the parents as ‘real’ parents, bereavement photography might also help to affirm the grief experienced by parents who have lost a newborn. One parent in the current study articulated this concept beautifully. When asked what her photographs meant to her, she simply stated “I have something to grieve”. Having undeniable evidence of their baby’s life helped to validate the intense grief experienced by bereaved parents in the current study.

Similarly, Blood and Cacciatore (2014) explored the views of 181 bereaved parents regarding bereavement photography. They reported that postmortem photography supported parents in “clarifying their ongoing identity as parents. Data also indicate that others’ acceptance and legitimization of their parental grief were important to mourning.” (p.231). This function of bereavement photography was also described by Bennett et al. (2008) who explained that many parents “feel the world goes on as though their child, and their role as a parent, was not just lost but never existed” (p. 486). In this sense, photographs may help not only to validate the child’s existence, but also to validate the profound sense of loss and grief experienced by neonatally bereaved parents.

Finally, parents in the current study described the role of photographs in helping create a space for their baby within the family unit. Several parents described having photos of the infant they had lost alongside the baby pictured of their surviving children. For other parents, photographs which captured the dying infant with both parents and surviving siblings were uniquely meaningful, representing the only time the ‘whole’ family were able to be together.

The role of photographs in positioning the lost infant within the family has previously been described in the literature. For example, Godel (2007) argued that photographs of stillborn infants aid in “reconstructing the disrupted biography of the family to include the dead child, thereby allowing him or her to be remembered, mourned and memorialized” (p.253). Photographs provide a way of integrating the lost infant into the family, marking their permanent position as a son or daughter, brother or sister.

Bereavement photography was a critical element of ‘creating evidence’ for parents in this study. Photographs help to create an identity for the baby and position them within the family, to legitimise the role of participants as parents to *this* baby, and to validate the intense grief experienced by parents whose babies had died. All of these functions act in concert to affirm parenthood in the context of neonatal loss.

8.4.2 Collecting or creating mementos

In addition to photographs, all of the parents in the current study had other items which acted as keepsakes or mementos. These mementos were significant to parents in a number of ways. As with photographs, mementos provided a form of evidence that their baby was real. Parents expressed deep feelings of unreality after delivering a baby, and

then leaving the hospital with empty arms. Having mementos, particularly those which captured unique aspects of the baby's appearance, such as footprints or locks of hair, were valuable in affirming that this baby *did* exist, and that they *were* a real person.

Parents in the current study also described specific mementos which helped to provide a sense of identity for their baby. For instance, items of clothing worn by the infant, which gave some sense of the size of the baby, and which sometimes retained their scent, were treasured by some parents and stored away carefully to retain their integrity. For these bereaved parents, tangible items such as clothing became evidence of their existence, and their fundamental personhood, which could be kept and handled long after the baby was gone.

A similar concept was described by Gibson (2004) who described items such as clothing or personal possessions belonging to the deceased as 'melancholy objects'. She explained that "Because clothing is imprinted with the size, shape and odour of the lived body it has a power of immediacy that perhaps photographs lack" (p.290). This insight may help to explain the particular significance that parents placed on items of clothing that had been worn by their baby.

Several parents in the current study also mentioned the importance of items such as cot-cards or ID bracelets which bore their infants' name. This concept was explained simply by one father; "she's a person. She's got a name". This use of the baby's name helped to establish a unique social identity for the infant and in doing so affirmed their significance as a person who could be loved and mourned. While a number of guidelines and articles recommend keeping items such as cot-cards or ID bands for parents, none of

these sources explored the particular role of such mementos in helping provide a sense of identity for the lost child.

Finally, parents in the current study explained that mementos helped make their baby, and therefore their loss, real for other people who might not have seen the baby while they were in the neonatal unit. Several parents commented that having tangible items, such as footprints, allowed others to appreciate that they had given birth to a ‘real’ baby and had also experienced a ‘real’ loss.

While parents were generally grateful for the mementos they received, some interesting preferences were identified during the current study. For instance, the tactile nature of some mementos was described as valuable by parents. One example of this emerged with regard to footprints. All of the families in this study had ink-based prints (2-dimensional images) of their baby’s feet. However, some families also received imprints made of clay or plaster that captured the texture and creases of the foot, which could then be felt as well as seen. Those with ink-based prints were grateful for these, however, imprints were identified by parents as particularly valuable, primarily because of their more tactile nature. Having something to literally “hold on to” was comforting for parents. These items also provided a sense of the infant’s size and physicality that may have been more difficult to establish through photography alone. Although parents in the current study expressed a strong preference for tactile mementos such as clothing, blankets and imprints, no studies were identified which explored these preferences among neonatally bereaved parents.

The other interesting preference expressed by parents in this study was around receiving a lock of hair as a memento. While several parents expressed gratitude for this item, a few were distressed that their baby's hair had been cut, often without their knowledge or consent. Unlike taking photographs or creating footprints, cutting the baby's hair caused an irreversible change to the baby's body; as such it was important to some participants that they consented to this element of memory-making. This finding was of interest as limited literature specific to the use of a lock of hair as a keepsake could be identified, beyond the recommendation to offer this to parents. Layne (2000) describes hair as having been a memento of lost or absent loved ones in western culture since the 18th century. She explains that hair functions as a 'safe' and enduring way to retain a part of the person's physical being. Further exploration of parents' perceptions of hair as a memento are warranted, as little empiric evidence exists to guide practice in this area.

All of the parents in the current study described creating or collecting mementos of their baby's brief life and death. As with photographs, mementos acted as evidence of the baby's existence, however the tangible nature of some mementos allowed them to capture aspects of the baby's physical being, such as their size, or the creases and folds of their feet, which also helped to mark them as unique individuals. Mementos which reflected moments of caregiving, such as items of clothing carefully chosen for the child, were especially precious to parents and helped to affirm their sense of parenthood.

8.4.3 Involving others

Parents in this study described bringing others in to the NICU to “meet” the baby, either while the baby was alive or after their death. Having others who remembered the baby and who recognised them as a unique individual helped to affirm the baby’s identity and validate the sense of loss experienced by the parent. Involving others was sometimes an informal process that typically included meeting the baby and ‘saying goodbye’, but parents in this study also described involving others through faith-based rituals such as a baptism or blessing. For the parents in this study, involving others was important as a way to ensure their baby’s memory lived on, not only within themselves but also within friends and family.

Guidelines are increasingly recognising the value of involving others in perinatal end-of-life care. For example, the Canadian Paediatric Society’s (2001) perinatal loss guideline states:

It is important that, at some point, relatives or friends be allowed to see the baby, with the parents’ approval. Indeed, these individuals can validate the infant’s existence and death, thereby acknowledging the parents’ loss and their need for grieving. (p.472)

Having others ‘meet’ the baby, whether before or after death, appears to support affirmation of the baby’s existence, as well as affirmation of the loss experienced by perinatally bereaved parents.

In addition to having friends and extended family meet the baby, several parents in the current study discussed the decision to involve the baby's siblings in end-of-life or post-mortem care. For some parents, including their older children in care of the baby was a treasured memory, especially where the siblings were old enough to anticipate the birth of the baby and experience their own sense of loss and grief when the baby died. Several other parents chose not to involve their other children in their baby's final hours or days, either because they felt the siblings were too young to understand what was occurring, or because they were concerned about the impact that the experience of meeting the dying baby might have on the siblings' mental health. While most parents were comfortable with their decision to exclude their other children from the end-of-life or postmortem care of the baby, for others, this was a source of self-doubt and even regret.

A small qualitative study by Fanos, Little and Edwards (2009) reported that siblings whose infant brother or sister had died in the neonatal unit when they were young were aware of the impact of the loss on their parents, even when the loss was not openly discussed. The majority of these siblings also treasured photos of their lost brother or sister; for some this was the only concrete evidence of their existence, while for those old enough to remember the infant, the photos were cherished as reminders. While more evidence is needed around involving siblings in memory-making interventions, it appears that allowing children to keep mementos from their lost sibling and permitting them to participate in bereavement related rituals may be beneficial.

In addition to having others 'meet' the baby, sharing and displaying photographs or other mementos was another common strategy for involving others among participants in this study. Parents interviewed via phone or Skype spoke in detail about the items that they had on display. Similarly, parents who were interviewed in their own homes pointed out favourite photos or mementos on display in living rooms or kitchens. While most parents did not articulate *why* they had chosen to keep these items in the living areas, some parents indicated that having mementos or photos on display helped to ensure their baby would not be forgotten. These items also served as a way of introducing the baby to others who had not met them during their time in the neonatal unit.

The significance of sharing mementos with others has also been explored in the literature. Crawley et al. (2013) described the importance of making and sharing memories in the context of mothers bereaved by stillbirth. The authors explained that sharing memories may allow the mother to "adapt her narrative identity to include the baby and the role of mother in a healthy way" (p.203). They add that perinatal loss:

is an example of ambiguous loss (Boss, 1999). This leads to ambiguity in the mother's identity – she is both 'mother', the baby was born and is psychologically present, and 'not mother', the baby is physically absent. Sharing memories may help women resolve the ambiguity." (Crawley et al., 2013, p.197)

While Crawley et al. explored the impact of making and sharing of memories on the bereavement experiences of mothers after stillbirth rather than neonatal loss, a similar need for integration of identity, and validation of parenthood from others, was evident in the stories of participants in the current study.

The majority of parents in the current study expressed the importance of collecting as many mementos as possible, even though some mementos would prove to be more meaningful than others over time. As opposed to the loss of an older infant or child, who would typically have a bedroom filled with personal possessions, the loss of a newborn resulted in a brief window of opportunity for memory-making, and a dearth of items that held meaning for the family and anchored their memories in a physical sense. Participants in the current study generally recommended that parents and/or staff collect all items which could potentially act as mementos, enabling parents to select those with personal significance to keep or display.

A similar need to collect all items that might act as mementos, and which therefore affirm parenthood, was reported in a study by Cacciatore (2010). The author reported that for women experiencing stillbirth, “there are few tangible artefacts to remind her of the baby, and she may desperately cling to anything that recognises and validates her sense of motherhood” (p.142). Conversely, a number of authors have described the sadness and regret experienced when parents are refused items which have taken on personal significance, such as hospital blankets or caps, or when potential keepsakes are discarded or misplaced (Downe et al., 2013; Nordlund et al. 2012). This highlights the importance of providing parents with any item which might be meaningful and allowing parents to then identify items with particular significance in their own time.

‘Creating evidence’ was accomplished by parents in the current study through the collection or creation of mementos, through bereavement photography, and also through involving others during the NICU stay. Each of these forms of evidence acted to affirm the baby’s existence, to affirm the parental role and to affirm the grief experienced by

bereaved parents. The findings of the current study are well aligned with the existing perinatal bereavement literature and contribute to current understandings of the impact and significance that photographs and other mementos hold for parents experiencing the death of a newborn.

8.5 BEING GUIDED

Parents in the current study expressed a need for guidance, both to act as parents to their baby and to collect evidence of their baby's brief life. Where parents received sufficient guidance, they were appreciative of the care provided, and described their memory-making experiences in positive terms. Guidance enabled parents to engage in memory-making activities that affirmed their role as parents, and affirmed the significance of their baby's life and death. Conversely, inadequate guidance resulted in missed opportunities for parenting the baby and lost mementos that often could not be replaced or recovered.

8.5.1 Needing guidance

Parents in this study experienced profound shock at their baby's (often very preterm) delivery, their separation while the baby was transferred to NICU, the unfamiliar and starkly clinical environment of the NICU, and their fear and sorrow at their baby's illness and death. Parents described this shock as impacting adversely on their capacity to make decisions about memory-making as part of their baby's end-of-life care. These parents explained that they were reliant on staff to support them in parenting their baby and creating evidence of their baby's brief life.

A similar finding was reported by Carlson (2012). She found that parents whose babies were receiving end-of-life care were frequently “unprepared, overwhelmed, and they rely on their nurses’ expertise to guide them” (p.87). Indeed, providing suggestions has been found to facilitate perinatal end-of-life care that is meaningful to the family. Cacciatore & Flint (2012) reported that perinatally bereaved parents in their study “indicated that they did not know what to do and wished that someone ‘in authority’ would have guided them in their decision-making process” (p.165). Rather than being provided with options in a neutral way and being left to make decisions independently, parents, both in the current study and in the broader literature, have expressed a need for active guidance around the time of their baby’s death.

While the majority of papers recommend that staff provide suggestions around end-of-life care, there remains a significant tension for health professionals between providing sufficient guidance to ensure that parents do not miss the limited opportunities to build memories with their baby, and the fear of “forcing” vulnerable parents to engage in unwanted or inappropriate interventions (Gravensteen et al., 2013; Henley & Schott, 2008; Rådestad et al. 2009). However, this trend toward caution in the literature has undergone a subtle shift over the past decade. More recent research findings suggest that parents are grateful when staff actively encourage memory-making, even in the face of initial reluctance (Abraham and Hendriks, 2017; Cacciatore & Flint, 2012; Kelley and Trinidad, 2012).

The need for a more nuanced approach to guiding parents through memory-making in neonatal end-of-life care is also being acknowledged in neonatal palliative care guidelines. For example, the online Neonatal eHandbook, produced by the Victorian

Department of Health and Human Services (2014), states that parents and siblings should be provided with opportunities to engage in caregiving with their baby, and add that:

Some parents may not wish to do so and should not be forced. It is usually worth exploring why they do not wish to do so. Sometimes it is for cultural reasons or some parents may just need extra time, reassurance and support to overcome their fear.

This approach acknowledges the need to explore parents' needs or concerns around memory-making, rather than leaving parents to make decisions without adequate information or support.

A number of studies report a similar need for gentle but repeated guidance toward memory-making activities in perinatal end-of-life care (Downe et al, 2013; Abraham & Hendriks, 2017). For example, Abraham and Hendriks (2017) describe parents' perceptions of spending time with their baby after death. They found that "Looking back, parents felt glad that the HCPs encouraged or even pushed them to spend time with their deceased baby in one way or another, even though it was something some parents initially felt hesitant about" (p. 2107). It is particularly telling that the word "pushed" is used by Abraham and Hendricks, as the same word was used repeatedly by participants in the current study. Several parents explained that staff "gently pushed" or "politely pushed" them to engage in memory-making, or "made sure" they had collected and created sufficient mementos of their baby. Rather than being regarded as a negative aspect of the experience, this active and repeated encouragement to engage in memory-making was spoken about with a sense of gratitude, both by the parents in this study and participants in previous research.

Parents in the current study identified that they needed guidance around memory-making in part because they were so overwhelmed during their baby's time in the neonatal unit. However, this was not the only reason that parents expressed a need for guidance. A number of parents also stated that they did not understand the purpose or significance of memory-making until months or years into their bereavement. These parents explained that taking photographs was 'the last thing on their mind' at the time of their baby's death; without adequate guidance, these photographs and mementos would potentially have been lost forever.

A similar pattern emerged in a study of neonatally bereaved parents by Martel and Ives-Baine (2014). They report that: "While half of the participants had been taking photos or asking nurses to take photos right from the outset, the other half admitted photography was the 'last thing on their mind' or 'didn't seem relevant at the time'" (Martel & Ives-Baine, 2014, p.321) This highlights the importance of active guidance around memory-making for parents experiencing the loss of an infant, even when this does not appear to be a priority for the parents at the time.

While supporting autonomy and encouraging parents to engage in decision making are laudable goals, it is important to acknowledge that parents who are overwhelmed by their baby's illness and death may not be able to appreciate the significance of the memory-making activities offered, and may experience regret about opportunities lost, or items not collected, long after their baby's death. It is unreasonable to expect parents to be familiar with the options for memory-making that are available to them, or to appreciate the potential impact of such interventions may have on the course of their grief weeks, months or years into their bereavement. Providing sensitive but

active guidance is important in minimising the risk of regrets and optimising bereavement care for parents.

8.5.2 Receiving guidance

The majority of participants in the current study felt that they had received adequate guidance from the nurses, social workers and other staff in the neonatal unit. Where parents received active guidance, they described care as empathetic and supportive. Even when participants declined a specific memory-making intervention, they were grateful that these options had been presented. This finding is consistent with the perinatal bereavement literature. Lemmer et al. (1991) explored parents' perceptions of caring following perinatal or neonatal loss. They report that parents felt cared for when health professionals facilitated the creation of memories, and specifically identified bereavement photography as an intervention which demonstrated caring.

Guiding parents to participate in the collection or creation of mementos was also identified as helpful by several parents in the current study. For instance, several mothers were supported to participate in taking footprints from their babies and were grateful for this experience. Another participant was disappointed that she had not been invited to participate in collecting mementos, as this experience would have given her another way to engage with her baby, and as such would have provided a positive memory to reflect on after her loss. Where possible, inviting parents to collect mementos or participate in creating mementos may be a useful strategy.

Parents' desire to be included in the collection and creation of mementos has not been explored in detail in the literature. The majority of guidelines and articles describe mementos being collected by staff and being "provided" or "given" to the family

(Callister, 2006; Canadian Paediatric society, 2001; Harden, 2018; Kavanaugh & Moro, 2006; Stevenson et al. 2017). Conversely, Cholette (2012) describes supporting parents to participate in memento creation “to help authenticate and actualize the true existence and death of their child” (p.36). She argues that the act of creation in itself may affirm the life and loss of the baby for bereaved parents. Guiding parents through the process of memento creation may be an underutilized strategy in current clinical practice. However, as with other aspects of memory-making, there is a need to acknowledge that not all parents will have the capacity or desire to engage in the collection or creation of mementos and may wish these to be curated by others.

While the majority of parents in the current study felt they had received adequate guidance, some identified situations in which guidance was tentative, half-hearted or otherwise lacking. These instances gave rise to feelings of regret around opportunities for memory-making which had been lost, and which could not be recovered. As described earlier, this relationship between a lack of guidance and later regrets has previously been described in the literature (Abraham & Hendriks, 2017; Cacciatore & Flint, 2012). Helping parents to understand how they can contribute to their child’s care, and to appreciate the importance of collecting or creating mementos, are critical elements of guidance that act to enhance memory-making.

One aspect of memory-making which requires special attention is the contact between parents and their baby who has died. Several parents in the current study explained that they were worried about being viewed as morbid or unbalanced for wanting to spend time with their baby’s body after death. These parents felt that more reassurance and support would have enabled them to spend more time with their baby

after death, improving their experience of memory-making. This need for guidance and support around contact with the body after death was described by Nordlund et al.

(2012) who reported that for mothers of stillborn babies:

Support and encouragement from professionals were important to mothers when deciding if they would be able to hold and spend time with the baby after birth. Mothers expressed sadness when they felt health professionals did not support them in taking time to bond with their baby. (p.781)

Parents who are not supported and encouraged to spend time with their baby after death may experience sadness or regret that may persist in the years after their loss, while active guidance may help parents to say a meaningful goodbye.

Active guidance around memory-making is an important element of care for parents experiencing the death of an infant in the neonatal unit. Where guidance was active, and where repeated offers for memory-making were made, parents perceived staff as caring and supportive. Conversely, parents who received limited guidance described feelings of regret, arising from lost opportunities to parent their baby and to create evidence of their existence. Active guidance promoted parents' participation in memory-making, and in turn, supported affirmation of both the baby and the parents.

8.5.3 Culture, faith and memory-making in neonatal end-of-life care

Cultural and spiritual needs did not emerge as significant elements of parents' stories in the current study. However, culture, ethnicity, and faith must be considered as contextual factors that influence the impact and significance of memory-making interventions for participants. The majority of the parents in this study were of white

Anglo-Saxon or Angelo-Celtic origin and all were English-speaking, although detailed demographic data pertaining to participants' countries of origin were not collected. It may be that culture or ethnicity did not emerge as a core feature of parents' stories precisely because they largely identified with the dominant western culture. Because these parents were cared for in a system that was operating from a cultural perspective similar to their own, incidents of incongruity between care and the parents own preferences were described in terms of personal values and beliefs, or in terms of insensitive practice from individual health professionals, rather than being framed in cultural terms.

Similarly, faith-based needs and norms were evident in parents' stories but were not a dominant theme. Six of the eighteen parents described participating in some form of religious ritual within the neonatal unit, such as a blessing, christening or baptism. These rituals were meaningful in-and-of themselves and appeared to provide a sense of reassurance around the baby's spiritual journey for some parents. This finding is in keeping with research by Meert et al. (2005), who studied the spiritual needs of parents during end-of-life care in the paediatric intensive care unit. The authors report that parents most often requested a baptism or last rites as a way "to ensure their child's safe passage into the afterlife" (p.424).

For the majority of parents, these rituals were also described in terms of involving others. Engaging in spiritual rituals provided a mechanism to involve other people in the baby's life and to introduce the baby into their faith community. This potentially provided a way of developing a social identity for the baby that was salient to people other than the parents.

Multiple guidelines recommend offering parents the opportunity to engage in faith-based rituals during perinatal or paediatric end-of-life care (PSANZ, 2018; Canadian Paediatric Society, 2001). As described in the PSANZ guideline (2018):

Introducing the baby to the extended family, holding a 'baptism' or 'blessing' or naming service... are important parenting activities. These tasks are not just important in order to create memories or mementos, but to create a lifelong bond with the child that can endure beyond death. (p.60)

Enabling parents to engage in faith-based rituals may facilitate continuing bonds between the baby and their family.

Given the relative homogeneity of the sample in the current study, it is important to acknowledge that different needs and preferences around memory-making may have emerged with a more culturally, ethnically and spiritually diverse sample. Several authors have tried to provide general guidance around culturally sensitive or culturally safe bereavement care, in the context of paediatric perinatal or neonatal death (Chichester, 2005; Weiner, McConnell, Latella & Ludi, 2013). These authors typically caution that the collection or creation of specific mementos or activities such as touching, holding or bathing the baby or child, may be problematic or even distressing for people of particular cultural or religious backgrounds. For example, Chichester (2005) explains that for some parents of Amish faith, having photos taken of their child, whether living or dead, is potentially problematic. Similarly, for some Muslim families, having handprints taken or removing a lock of hair as a keepsake may be viewed as a form of desecration and are therefore generally not acceptable interventions (Arshad, 2004; Chichester, 2005). Interestingly, Chichester suggested that both Amish and Muslim families may wish to

bathe and dress or wrap their infant (or to have family members undertake these tasks) in preparation for burial. In this sense, some of the typical memory-making options offered in western hospitals may be inappropriate for some families, while others may be actively embraced as a familiar and desired element of bereavement care.

There is, however, some suggestion in the literature that rather than offering memory-making or other bereavement care options, that health professionals should simply ask parents what they want or need as a means of avoiding potential cultural or spiritual taboos. For example, Shaefer (2010) cautions that:

There is no 'magic formula' or 'cookbook' for working successfully with families of different cultures. The best approach is perhaps the simplest – ask family members, “How can I help you?” and then listen carefully to their answers. Each bereaved mother, father and family member may have different needs. (p.15)

Starting a conversation about bereavement care by enquiring about the family's needs and wishes is incredibly important. However, there is a significant risk that this approach on its own may deprive parents of the guidance that so many of the participants in the current study wanted. Over and over, parents in the current study described their shock and distress as barriers to decision making. Furthermore, almost all parents explained that they did not know what was available or what was socially acceptable, and many felt that they did not understand the value of memory-making interventions until well into their bereavement. Simply asking parents what they need, without providing a range of options or explaining why these might become important in time, leaves parents vulnerable to missing opportunities for memory-making that can never be recovered. Conversations with parents around bereavement care should start with an open enquiry

into parents' thoughts, feelings, and preferences around memory-making, but then extend into a sensitive discussion that teases out religious, cultural and personal convictions from the initial reluctance or uncertainty described by so many of the participants in this study.

8.5.4 Gender and memory-making in neonatal end-of-life care

As with culture, the impact of gender and perceived gender roles were an element of the subtext underlying each of the three key categories in the current study. There were insufficient examples of gender-based differences in memory-making needs or preferences to form a discreet category. However, there were times that gender, or perceived gender roles, seemed to influence parents' experiences of memory-making.

Fathers in the current study described similar key concerns around memory-making as mothers, although fathers sometimes concentrated on caring for their partner at the expense of their own emotional needs. In particular, several fathers 'protected' their partners from images that were potentially distressing, or that their partners were not 'ready' to see. These fathers were clear about experiencing their own profound sense of loss, however several fathers described the need to prioritise their partners' emotional needs over their own.

A similar theme was identified in the literature surrounding gender and perinatal grief. For instance, Badenhorst, Riches, Turton and Hughes (2006) conducted a systematic review of studies that had explored psychological outcomes for fathers who had experienced stillbirth. The reviewers found that although fathers experienced "classical grief responses" (p.245), providing for and protecting their partner emerged as a significant concern for fathers. Similarly, a systematic review of health outcomes in

fathers who had experienced perinatal loss found that “Qualitative studies indicated that men often feel that their role is primarily as a ‘supporter’ to their female partner, and that this precludes recognition of their own loss” (Due, Chiarolli & Riggs, 2017, p.1). These findings emphasise the need for health professionals to provide appropriate support for both parents during neonatal bereavement care, and to anticipate the potential for different needs or preferences between parents.

As described in Chapter Six, fathers were also more likely to experience ambivalence toward having photographs taken of their baby. At times these concerns arose from a need to protect the baby and the mother, as identified earlier. At other times, the concerns related to the nature and content of the photographs as somehow improper or morbid. Interestingly, despite this initial reluctance, all of the fathers who participated in this study were grateful to have photographs.

Within the small body of literature focused on memory-making interventions in perinatal bereavement, there is even less evidence to guide memory-making specifically with newly bereaved fathers. One study of 12 Australian men who had experienced a stillbirth found that for these fathers, memory-making was perceived as valuable. The authors explain that:

The holding of their baby allowed the fathers to realize the baby was their child and various rituals, such as talking, bathing, playing, touching and photographing their baby were significant in allowing the men to reconcile the stillbirth experience with their fathering identity. (Bonnette & Broom, 2011, p. 257)

This finding clearly resonates with the findings of the current study, suggesting that affirmation of the parents' identity is equally important for bereaved fathers as bereaved mothers.

In a selective review of the literature, Cholette (2012) argues that "both parents should be given the opportunity to be actively involved in the creation of memories, and mementos to help authenticate and actualize the true existence and death of their child" (p.36). While both fathers and health care workers tend to focus on the needs of bereaved mothers, it is critical that fathers are supported and encouraged to participate in parenting their baby and collection or creating mementos, to whatever extent they are comfortable with. Providing time to make decisions around memory-making, and to become accustomed to ideas such as bereavement photography, may also be useful when supporting bereaved fathers.

8.6 CONCLUSION

This chapter has highlighted each of the three key concerns that were evident in these parents' stories of memory-making in neonatal end-of-life care: Being a parent, creating evidence, and being guided. Where parents were actively guided to have contact with their baby, to engage with them and to provide care, they felt that the significance of their baby's life and their own role as parents had been affirmed. Similarly, where parents were effectively guided to collect evidence of their baby's existence, they experienced validation that their baby's existence as real and significant, and their identity as parents was affirmed. Parenting activities and evidence of the baby's life also acted to validate parents' loss, which may also impact on the social support available in

bereavement. In the following chapter, it is argued that “affirmed parenthood” is the basic psychosocial process that explains the impact and significance of memory-making in the lives of parents experiencing the loss of their newborn infant.

Chapter 9: **Conclusions**

As described in the previous chapter, three key elements of memory-making emerged as significant to parents experiencing the loss of a newborn; ‘being a parent’, ‘creating evidence’ and ‘being guided’. These three elements are connected through, and underpinned by, the core category ‘Affirmed Parenthood’. In this chapter, a substantive, or localised, grounded theory is presented which explores the basic psychosocial process of affirmed parenthood. The links between this core category and each of the elements of memory-making in the context of neonatal end-of-life care are also explored. The potential implications for practice arising from the substantive theory affirmed parenthood are discussed, and limitations or barriers to practice change are described. The strengths and limitations of this study are examined, and finally, potential directions for future research are explored.

9.1 IDENTIFICATION OF THE CORE CATEGORY: AFFIRMED PARENTHOOD

As described in Chapter Four, the core category is a unifying theme that “represents the central phenomenon of the study” (Corbin & Strauss, 1990, p. 424). Within a grounded theory, the core category acts as the fundamental concept that connects all of the categories and subcategories that emerged during constant comparative analysis of the data. It is the development of this core category, and the

explication of the connections between concepts, that provides a grounded theory with the capacity to explain, as well as describe, the phenomena under investigation.

In the current study, the basic psychosocial process underpinning the three themes “Being a Parent”, “Creating Evidence” and “Being Guided” was identified as “Affirmed Parenthood”. Affirmation is a complex concept with multiple meanings. Firstly, to affirm can mean “to state something as true” (Affirm, Cambridge Online Dictionary, 2018) or “to make valid” (Affirm, Collins Online Dictionary, 2018). Engaging in memory-making activities before, during and after the death of their infant provided affirmation for parents in this study on a number of levels.

Firstly, memory-making affirmed for parents that their baby was a real person. The creation and collection of photographs and other mementos provided enduring evidence of the baby as an individual worthy of love and respect. Mementos that captured unique traits of the baby, that positioned the baby within the family unit, or that were tangible and tactile, were particularly valued by parents as a means of affirming the essential reality of their baby.

Secondly, memory-making provided affirmation of parental identity and validation of participants’ role as parents. Activities such as spending time with the baby, touching or holding their baby, and providing physical care, allowed participants to bond with their child, and to step into their role as a parent. Even seemingly small acts of caring, such as choosing the baby’s clothing emerged as potentially important opportunities for participants to become parents to their baby.

Finally, memory-making interventions provided affirmation of the significance of parents' loss. As the baby's identity was constructed and confirmed, and the role of the parents was validated, their loss became a 'real' loss. This validation transformed the death of the infant from a private tragedy to a bereavement which could be socially acknowledged and publicly mourned.

Therefore, where participants received adequate guidance to parent their baby and to create evidence of their baby's life, affirmation occurred: affirmation of the baby's existence, affirmation of the bond between parent and child, and affirmation of the loss endured by the parents. This model of "Affirmed Parenthood" in memory-making in neonatal end-of-life care is presented in Figure 1.

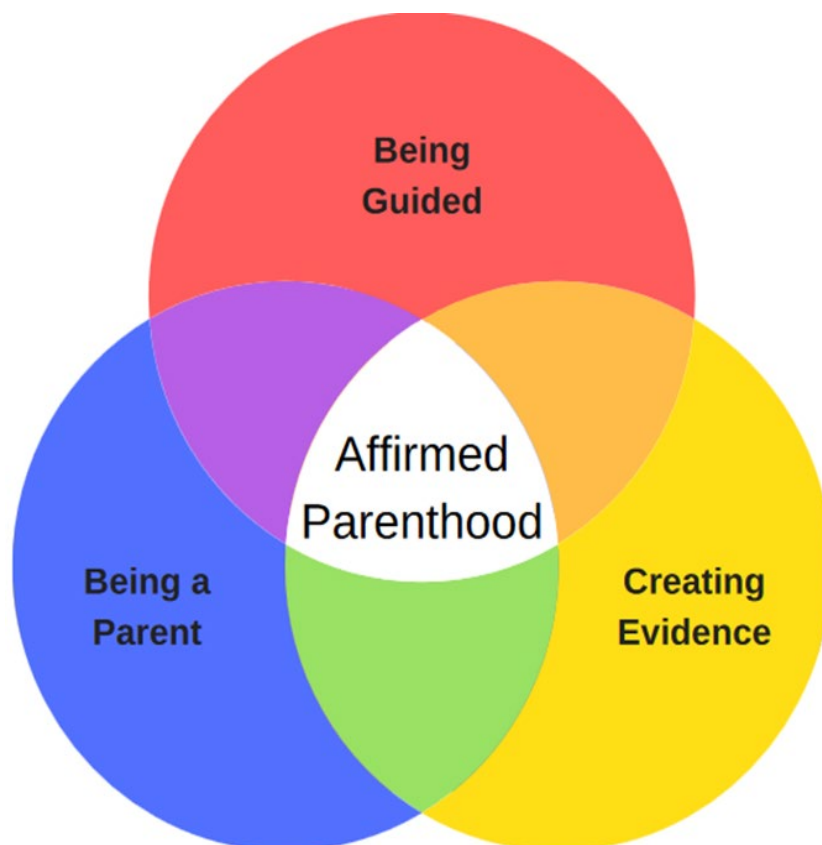


Figure 1. Affirmed Parenthood as the core psychosocial process of memory-making in neonatal end-of-life care

As evident in Figure 1, each of the three elements of memory-making (being a parent, creating evidence, and being guided) needed to be in place in order for affirmed parenthood to occur. However, these concepts did not emerge independently of one-another; significant interactions between each of the elements of memory-making were also apparent. Perhaps the most obvious of these interactions was between being guided and both being a parent and creating evidence. Parents needed to be supported and encouraged to hold and touch their baby, especially when they expressed concerns about causing pain, triggering a deterioration in their baby's condition, or even hastening their baby's death. Parents also needed to be guided through the act of providing care for their baby. Simple acts of caregiving, such as washing, dressing, or changing nappies, were rendered more complex by the NICU environment and the multitude of tubes, lines and wires that many babies were connected to prior to their deaths. Participants required active direction and reassurance to undertake these acts of caregiving which enabled them to become parents to their baby. Parents expressed deep gratitude to staff who recognised the importance of parent-child interaction and created or facilitated opportunities for parenting.

Parents also described their need to be guided through the creation or collection of photographs and other mementos. As explained they were often unaware of options, such as bereavement photography or the creation of footprints, until these were offered by the staff. Some parents also reflected that at the time of their baby's death, they did not understand the significance that mementos and photographs would hold for them in the months and years after their loss. Parents were grateful to staff who had ensured these items were collected or created, even though this was often not a priority for the parents at the time of their baby's death. Where participants received active guidance to

create evidence of their baby's life, and to parent their baby, they experienced affirmation of their baby as a unique and important individual, and of their own role as a parent.

The elements of memory-making 'being a parent' and 'creating evidence' also interacted in interesting ways. For example, several parents described photos or other mementos which represented moments of parenting as being especially valuable. Photographs taken while parents held or bathed their baby, or items of clothing lovingly chosen for this child, were important keepsakes that not only honoured the life of the baby, but also honoured the relationship between parent and child. Conversely, the act of 'creating evidence' provided opportunities for interaction between parents and their baby. Being involved in acts such as creating footprints further affirmed parenthood, while being excluded from these activities was described by some participants as a lost opportunity to engage with their baby.

The substantive theory 'Affirmed Parenthood' not only captures the key concerns of parents regarding memory-making in neonatal end-of-life care, but also accounts for the negative cases or outlying incidents within the data. For example, while parents were generally positive about the mementos they collected and those they were given, several parents received items that they found distressing. These items were typically photographs which represented missed opportunities for parenting, such as images of others dressing or bathing the baby. These incidents provide important insight into the substantive theory 'affirmed parenthood'. While 'creating evidence' typically supported 'affirmed parenthood', mementos or photographs which represented missed

opportunities 'being a parent' interfered with that affirmation, and were therefore experienced as upsetting rather than helpful by bereaved parents.

9.2 CURRENT CONCEPTUALISATIONS OF "AFFIRMED PARENTHOOD"

The concept of affirmed parenthood was central to bereaved parents' experience of memory-making in neonatal end-of-life care in the current study. Interestingly, this concept of affirmation is also evident within the perinatal bereavement literature. For example, the role of mementos in validating or affirming the essential reality of the infant is evident in studies exploring parents' experiences of stillbirth or perinatal loss (Godel, 2007; Lathrop & VandeVusse, 2011; Uren & Wastrell, 2002). Uren & Wastrell (2002) explain that parents experiencing perinatal loss frequently describe the value of mementos in "affirming their baby's existence" (p.284). Not only do mementos affirm the existence of the baby, but they may also be used to create a social identity for the baby. As described by Godel (2007) parents experiencing perinatal loss use mementos, such as photographs, to visibly assimilate lost loved ones into their ongoing lives, "affirming the continued social identity of the dead person in the absence of a physical body" (p. 254).

The significance of caregiving experiences in affirming the existence and identity of the baby has also been explored by a number of authors. Brownlee and Oikonen (2004) explain that in the context of practical support for perinatally bereaved parents, "Equally important are steps taken to affirm the reality of the child. Parents are encouraged to hold, touch or see their baby who has died in order to substantiate the child as a member of the family" (p. 521). In a selective review of the literature, Harden (2018) explains that "Validation of the relationship between the mother and the baby affirms the relationship

through acts of caregiving such as swaddling, bathing, cuddling, and kissing” (p. 20).

Finally, the concept of affirmation was central to Lathrop and VandeVusse’s (2011) exploration of mother’s narratives of perinatal hospice. In particular, support from health professionals to collect or create mementos, and to engage in caregiving with their baby was described by participants as providing affirmation of the role of the mother, the worth of their babies, and the significance of their loss. While mementos are useful in affirming the reality of the child, it is arguably the interaction between parent and child that truly affirms their relationship, and therefore validates the intense feelings of loss experienced by perinatally bereaved parents.

While the concept of affirmation is not new in the perinatal bereavement literature, no previous studies were located which focused on the relationship between affirmation and memory-making in the context of neonatal end-of-life care. The findings of the current study suggest that memory-making provides affirmation of the existence and importance of the baby as an individual, and affirmation of the role of the parents. In doing so, the profound sense of loss and grief experienced by parents is also affirmed and can therefore be socially acknowledged. This study advances this existing knowledge by creating a clear and explicit theoretical framework that demonstrates how each element of memory-making contributes to a sense of affirmed parenthood for parents experiencing the loss of a newborn.

9.3 IMPLICATIONS OF THE SUBSTANTIVE THEORY “AFFIRMED PARENTHOOD” FOR HEALTH PROFESSIONALS

The substantive theory of ‘affirmed parenthood’ has important implications for health professionals’ support of memory-making practices in the context of end-of-life care in Australian neonatal units and potentially in neonatal units internationally. The substantive theory of affirmed parenthood highlights the need expressed by bereaved parents to spend time with their baby, to have physical contact with them, and to engage in caregiving as parents. This theory also captures the need described by parents to collect or create photographs and other mementos that act as evidence of their baby as a real person to be loved and mourned. Perhaps most importantly, the theory of “Affirmed Parenthood” emphasises the importance of gently but repeatedly encouraging parents to engage in acts of caregiving, and the importance of creating such opportunities whenever possible.

Most parents identified that time spent touching or holding their baby, and the experience of providing care for their baby, was the most significant aspects of their memory-making experience. Prioritising parents’ contact with their baby, recognising potential opportunities for parenting, and acknowledging the importance of the parents’ every-day engagement with their child, enhances parents’ experience of neonatal end-of-life care, and affirms the individual’s role as the parent of this baby.

These findings also present a call to action to ensure that small opportunities for parenting are not neglected. For example, the act of choosing their baby’s clothing emerged as important to parents in this study, however in practice this task is often performed by staff. Providing parents with an array of outfits and encouraging them to

select their baby's clothing is a simple strategy, yet such small acts may provide powerful affirmation of the parental role.

With regard to the significance and impact of mementos, the substantive theory of "Affirmed Parenthood" may help to explain why parents are generally positive about mementos but place particular value on items that had a clear connection with their baby. Items that had been in physical contact with their baby, items that captured the unique aspects of their baby, such as name-tags from cots that included the baby's name, or photographs that provided a clear view of the baby's face, were particularly meaningful to parents in this study. These items, which provided a sense of identity for the baby, helped to affirm the baby's existence as a real and significant individual. This in turn provided affirmation of the role of the parent, and provided validation of their baby's death as a real and significant bereavement. The concept of affirmed parenthood provides important direction for prioritising the collection of personalised mementos to improve parents' experience of bereavement care.

Mementos that had tactile qualities, and that could be touched or held were also identified as being of particular significance by parents in this study. From a practical perspective, this may mean collecting clay or plaster imprints of the baby's hands and feet in addition to ink-based prints. Intentionally dressing the infant in more than one outfit either before or after their death may also allow parents to keep items of clothing that were worn by their baby, and that therefore act as a tactile reminder of their child. Parents in this study were grateful for the vast majority of items created or collected in the neonatal unit as potential mementos, however this study provides useful guidance as to those items that may hold special significance.

Parents in this study also described involving others as a way of creating evidence of their baby's brief life and of their own role as parents. Interestingly, several parents commented that they were uncertain about inviting family and friends into the NICU space but all of the parents who included others in their baby's end-of-life care were glad that they did so. Actively encouraging parents to involve others in their baby's end-of-life care is another important strategy that may provide social affirmation of the existence of the baby as a 'real' person and the role of the parents as 'real' parents.

Perhaps the most important implication for practice to arise from this study is the need for health-care providers to take an active role in guiding parents through the process of memory-making in neonatal end-of-life care. While guidance needs to be sensitive to the spiritual, cultural and personal needs of each parent, offering a range of memory-making interventions and providing multiple opportunities for parents to engage in memory-making emerged as critical to parents' experience of their baby's end-of-life care. Parents in this study identified that they needed active support and encouragement to engage with their baby and to provide care. These parents spoke highly of staff who facilitated opportunities for parenting. Similarly, parents described their need to be guided through the process of collecting or creating mementos, or to have these items curated on their behalf. Parents were overwhelmed at the birth and subsequent death of their baby and reflected that at the time of their baby's death, they did not understand the significance that mementos would hold for them later in their mourning. Given the brief window of opportunity for the collection or creation of mementos and the irreversible nature of many of the decisions made at this time, parents in this study relied on staff to ensure they created as much evidence as possible of their baby's life and loss.

Current healthcare doctrine emphasises the importance of patient autonomy and decision-making. However, parents in this study who were simply presented with options and left to make decisions about memory-making without adequate support were at times left with regrets about opportunities they missed or mementos they did not obtain. Conversely, parents who described being actively encouraged to parent their baby and to create evidence of their baby's life were deeply grateful for this guidance. While the unique needs and preferences of parents must be taken into account, this study emphasises that actively supporting memory-making in neonatal end-of-life care can help to affirm parenthood and thereby improve the quality of care for bereaved parents.

9.4 BARRIERS AND LIMITATIONS TO PRACTICE CHANGE

There are a number of potential barriers that may impact on the translation of this evidence into practice. The most significant of these barriers may be the prognostic uncertainty for many babies at the time of their admission to the neonatal unit. While babies are being evaluated and efforts are made to stabilise them, parents may be discouraged from handling the baby due to the baby's physiological instability. Several parents in the current study explained that it was not until hours or days into their baby's admission, and often once it was clear that the baby was unlikely to survive, that they were encouraged to hold their baby. Several studies have similarly identified that parents whose babies are cared for in neonatal units were not encouraged to hold or handle their baby until a 'diagnosis of dying' was made (*cf.* Armentrout, 2007; Abraham and Hendriks, 2017). An awareness of the significance of contact for parents may help health

professionals to prioritise physical contact between parents and their baby, even in the context of an elevated risk of deterioration.

From a practical perspective, a lack of resources may prevent optimal practice in memory-making. For example, several parents in this study did not have high quality photographs of their baby or only obtained these late in the infant's hospitalisation, due to a lack of access to a high-quality digital camera. In Australia, the not-for-profit organisation Heartfelt is working to make their qualified volunteer photographers more readily available to families in neonatal units across the country. This organisation also donates camera kits and undertakes training with health professionals to improve access to high-quality photographs to families in remote or regional areas. Improving awareness of organisations such as Heartfelt amongst neonatal health professionals may promote access to photographers or photography equipment which could support memory-making in neonatal end-of-life care. Several parents also described missing out on the opportunity to obtain hand or foot imprints from their baby as the plaster or clay kits needed to do this were not readily available. Given the value that such mementos hold for parents, a small investment from hospitals to purchase imprint materials could have a significant impact on bereavement care for parents.

Finally, the capacity of staff to balance the need to provide active guidance around memory making with the fear of 'forcing' parents to engage in inappropriate memory-making activities is a potential barrier to practice change. The emphasis on autonomy and patient choice which underpins the codes of ethical conduct for health professionals may act to discourage clinicians from actively encouraging parents to engage in memory-making if the parents are perceived to be reluctant, or may prevent clinicians from

making repeated offers to engage in memory-making over time. While care must be taken to avoid forcing parents to engage in memory-making activities which are against their personal, spiritual or cultural beliefs, parents in this study expressed a clear and sometimes unmet need for encouragement and support even in the face of reluctance or uncertainty. There is a need to provide support and education to health professionals providing neonatal end-of-life care so that they feel confident and comfortable straddling the tension between providing sufficient guidance while remaining sensitive to the needs of the individual parent.

Overall, parents in this study were positive about their experiences of memory-making in their baby's end-of-life care. However, there were a number of opportunities for further improvement identified. Simple changes to practice, such as prioritising parents' contact with their baby, supporting and educating health professionals to provide active guidance to families, and small investments in equipment, could have a significant impact on improving parents' experiences of memory-making in neonatal end-of-life care.

9.5 STRENGTHS AND LIMITATIONS OF THE CURRENT STUDY

9.5.1 Strengths of the current study

The primary strength of this study is its unique contribution to the Australian and international literature around memory-making in the context of neonatal end-of-life care. This was achieved through the collection of rich and deep data in the form of parents' stories, and through sensitive analysis of the data, in keeping with the principles of the grounded theory method espoused by Corbin and Strauss. Care was taken to

engage in the coding processes they have outlined, and rigour was enhanced by engaging in constant comparative analysis at all levels of coding (see Chapter Four).

A careful balance was also maintained with regard to reading of the literature. Wide reading around the subject was undertaken at the beginning of the project to enhance theoretical sensitivity, while the more detailed and critical examination of the literature presented in Chapters Two and Three was avoided until after data analysis was completed to minimise the risk of “importing” concepts from the literature. This process helped to ensure that the theory remained firmly grounded in the data.

This adherence to the method is also evident in the use of theoretical sampling to the point of saturation for each of the three key themes. As described in Chapter Four, theoretical sampling is the process by that each sampling decision is made on the basis of testing or “filling in” emerging categories. Data collection and analysis were conducted until each of the three key categories and their subcategories were well described, and until the core category “Affirmed Parenthood” was identified and conceptually well developed. The decision to conclude sampling was only made once the student researcher was confident that the theoretical model arising from the project was robust enough to be of clinical use and that further sampling would yield little or no new information.

Another potential strength in this project stems from the background of the student researcher. Corbin and Strauss (2015) acknowledge that the experience and professional knowledge of the researcher can be used as a source of theoretical sensitivity, making the researcher more aware of nuances within the data and making them more sensitive to unusual or unique incidents within the research context. My own

professional background as a paediatric and neonatal nurse provided some useful insights into the data. For instance, recent experience in neonatal palliative care made me aware of variations in practice between units and helped me to differentiate typical episodes of care in any NICU context from care delivery specific to the dying infant and their family. In addition, extensive experience caring for dying infants and children and their families provided me with a sense of confidence in discussing difficult topics and in communicating in a sensitive way with bereaved parents.

Finally, memos were kept throughout the research process as a means of elucidating themes and enhancing auditability. As described in Chapter Four, memos are a means of exploring the data and developing the dimensions and properties of categories, as well as providing a mechanism for asking questions about the data and identifying relationships between concepts (Corbin & Strauss, 2015). During data collection and analysis, theoretical memos were linked with relevant codes or categories within NVivo, promoting transparency of the analytical process. Attention was also paid to documenting thoughts about the potential connections between categories and subcategories to ensure that the evolution of the substantive theory was captured adequately.

9.5.2 Limitations of the current study

One potential limitation of this study is the large proportion of “help-seeking” individuals who elected to participate. The decision was made to recruit via bereavement-related services for two reasons. Firstly, it was identified that there was significant variation in practice between health settings. Therefore, recruiting from a single centre may have impacted on the range of memory-making interventions that parents had

experienced and may not have captured important elements of current practice. Secondly, there was a concern that approaching parents via health services may lead parents to feel uncomfortable criticising practice, therefore distorting the parents' stories. While the decision to sample via bereavement related services did result in broader sampling, both at a participant and incident level, it must be acknowledged that parents who engage with bereavement-related service may not be representative of the broader population. In particular, it is possible that those who felt comfortable accessing or engaging with support services also held more positive views of memory-making interventions.

To minimise this effect, care was taken to approach a variety of parental bereavement services, including those that offer peer mentoring and professional counselling (e.g. SANDS and Red Nose) as well as organisations that offer practical interventions rather than psychological or social support (e.g. Heartfelt). It is also important to note that while parents were notified of the study via the social media sites or newsletters of these organisations, not all participants were actively "help-seeking". Indeed, several participants were "tagged" on a social media post by a friend or were reading the newsletter that had originally been delivered for their spouse when they came across the study information. In this sense there was a balance between individuals who were actively involved with peer support or other forms of assistance, and those who were not actively help-seeking within the sample.

Any parent who had experienced the death of a newborn in an acute neonatal unit in Australia was eligible to participate in the current study, regardless of the extent to which they were involved in memory-making activities. However, all of the parents who

contacted the student researcher to express an interest in participating had engaged in multiple memory-making activities, and all had largely positive experiences with this aspect of care. In part, this may reflect the ubiquity of memory-making activities in the context of neonatal end-of-life care. Simultaneously, these parents' positive response to memory-making interventions is well aligned with the research findings explored in previous chapters, which indicate that the overwhelming majority of parents value memory-making as an aspect of perinatal and neonatal bereavement care. Nevertheless, it is important to acknowledge that there may be parents who were not represented in the current study, who had a negative experience with memory-making activities, or who chose not to engage in memory-making at all. While the substantive theory "affirmed parenthood" helps to explain the impact and significance of memory-making interventions for parents who are open to engaging in these activities, this theory may not resonate with parents who hold strong personal, cultural or religious beliefs which preclude memory-making, or who have had a negative experience with memory-making interventions.

The absence of negative cases may in part be related to limited variation in culture or ethnicity within the study sample. As a theoretical sampling approach was used to direct sampling decisions, participants were chosen on the basis of their ability to contribute to the development of emergent concepts and themes, rather than on the basis of maximum variation, or stratification for culture or faith. This resulted in a relatively homogenous sample, with the majority of participants being of Caucasian or Anglo-Celtic descent. Due to financial and practical limitations, it was also necessary to restrict the sample to those who could be interviewed in English, further limiting the cultural diversity within the sample. Few participants discussed their faith in detail while

telling their stories, so it is unclear how diverse the sample was in terms of religious affiliation or beliefs.

It is important to recognise that individuals may hold values or beliefs informed by their cultural and spiritual heritage. In particular, most cultures and faiths have either explicit or tacit customs, or norms surrounding death and dying, and many have specific taboos or proscriptions around perinatal death. While cultural and faith-based needs did not emerge as a significant element of the stories of parents in this study, a more ethnically or spiritually diverse sample may have revealed different needs associated with memory-making in the context of neonatal death.

9.6 RECOMMENDATIONS FOR FUTURE RESEARCH

While this study contributes to understandings of memory-making in the context of neonatal end-of-life care, a number of important questions were raised during the research process that warrant further attention. In particular:

- How does culture and faith impact on parents' values, beliefs and preferences regarding memory-making in neonatal end-of-life care?
- How does the length of time between the infant's birth and death influence parents' experience of memory-making and on their preferences and needs before and after the baby's death?
- How many parents in Australian and international health settings refuse to engage in any form of memory-making, and what drives such decisions?

- How do current theoretical understandings of grief and loss help to explain the importance of memory-making for parents experiencing perinatal or neonatal loss?

Research into these areas could potentially enable health professionals to further refine and personalise care for bereaved parents, enhancing their experience of neonatal end-of life care.

9.7 CONCLUSION

The findings of this study indicate that memory-making activities can hold profound significance for parents in a number ways. Activities such as spending time with the baby, holding and touching them, and providing care are deeply significant, as these activities allow parents to step into the parenting role and affirm the identity of the individual as a parent to *this* baby. Simultaneously, creating evidence of the baby's brief life through collecting mementos, taking photographs or involving others in the baby's life and death holds significance for parents as a way to affirm the identity of the baby as an individual worthy of being loved and being mourned. Together these memory making activities impact on parents' experience of loss in a positive way, helping to affirm the parents' sense of loss and their right to grieve their baby. However, parents describe a number of barriers to memory-making in the context of neonatal end-of-life care. Parents are often overwhelmed by the birth and death of their infant and may not be aware of the options available to them or the importance of memory-making in the brief time they have with their baby. Parents require sensitive and personalised guidance through the

process of memory-making to ensure that these precious opportunities are not lost forever.

The substantive theory “Affirmed Parenthood” helps to explain the impact and significance of memory-making activities for parents in the context of neonatal end-of-life care. The findings from this study have the potential to provide valuable guidance for health professionals who are engaging in memory-making interventions, resulting in improved care for bereaved parents. This study makes an original and substantial contribution to the knowledge underpinning bereavement care for parents experiencing the death of their baby in a neonatal unit.

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Appendices

Appendix A: Ethics Approval

16 December 2014

A/Prof L.K. Harms
Social Work
School of Health Sciences
The University of Melbourne

Dear A/Prof Harms

I am pleased to advise that the Behavioural and Social Sciences Human Ethics Sub-Committee has approved the following Project:

Project title: **Memory making in neonatal end-of-life care**
Researchers: **A/Prof L K Harms, Dr P F Nicholson, R Thornton**
Ethics ID: **1443185**

The Project has been approved for the period: **16-Dec-2014 to 31-Dec-2015**

It is your responsibility to ensure that all people associated with the Project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

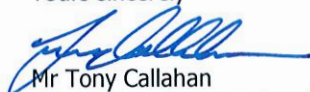
- (a) **Limit of Approval:** Approval is limited strictly to the research as submitted in your Project application.
- (b) **Variation to Project:** Any subsequent variations or modifications you might wish to make to the Project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised Project.
- (c) **Incidents or adverse effects:** Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the Project. Failure to do so may result in suspension or cancellation of approval.
- (d) **Monitoring:** All projects are subject to monitoring at any time by the Human Research Ethics Committee.
- (e) **Annual Report:** Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.
- (f) **Auditing:** All projects may be subject to audit by members of the Sub-Committee.

If you have any queries on these matters, or require additional information, please contact me using the details below.

Please quote the ethics ID number and the title of the Project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Yours sincerely



Mr Tony Callahan
Secretary, Behavioural and Social Sciences HESC
Phone: 8344 2067, Email: t.callahan@unimelb.edu.au

cc: HEAG Chair - School of Health Sciences



DEPARTMENT OF NURSING

Consent form for persons participating in a research

PROJECT TITLE: Memory-Making in Neonatal End-of-Life Care

Name of participant: _____

Name of investigator(s): Associate Professor Louise Harms (Supervisor); Dr Pat Nicholson (Supervisor); Ms Rebecca Thornton (PhD Student) _____

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.
2. I understand that after I sign and return this consent form it will be retained by the researcher.
3. I understand that my participation will involve an interview and I agree that the researcher may use the results as described in the plain language statement.
4. I acknowledge that:
 - (a) the possible effects of participating in the interview have been explained to my satisfaction;
 - (b) I have been informed that I am free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
 - (c) the project is for the purpose of research;
 - (d) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements;
 - (e) I have been informed that due to the small number of participants, it is possible that another person may be able to deduce my identity despite the removal of all identifying information from publications arising from this research;
 - (f) I have been informed that with my consent the interview will be digitally recorded and I understand that digital recordings will be stored at University of Melbourne and will be destroyed after five years;
 - (g) my name will be referred to by a pseudonym in any publications arising from the research;
 - (h) I have been informed that a copy of the research findings will be forwarded to me, should I agree to this.

I consent to this interview being digitally recorded

☐ **yes** ☐ **no**
(please tick)

I wish to receive a copy of the summary project report on research findings

☐ **yes** ☐ **no**
(please tick)

I prefer to be contacted via phone (provide number) _____

or email (provide email address) _____

Participant signature: _____

Date: _____

PLAIN LANGUAGE STATEMENT

Associate Professor Lou Harms (Supervisor)

Department of Social Work
ph: 8344 9413

Dr Pat Nicholson (Supervisor)

Department of Nursing
Ph: 9035 3438

Ms Rebecca Thornton (PhD Candidate)

School of Health Sciences
ph. 0409 407 898



Project: “Memory-Making in Neonatal End-of-Life Care”

Introduction

As someone who has had a baby who received end-of-life care in a neonatal unit, we would like to invite you to participate in our research project. The aim of the study is to investigate the process of memory-making (such as collection of mementos and taking of photographs) as part of end of life care in the neonatal unit. We are interested in how you view memory making practices, and whether you feel these practices have had an effect on your experience of loss. This project has been approved by the University of Melbourne’s Behavioural and Social Sciences Human Ethics Sub-Committee.

What will I be asked to do?

Should you agree to participate we would ask you to participate in an interview of about 60 minutes, so that we can get a detailed picture of the types of memory making activities you were offered and the effect that these activities have had on your experience of loss. With your permission, the interview would be digitally recorded so that we can develop an accurate record of what you say. The interview can either be face-to-face, or via telephone, or via Skype and will be at a time and place convenient to you.

Are there any risks involved in participating?

Because of the potentially upsetting nature of the topic, it is possible that being interviewed may cause you emotional or psychological distress. If this occurs, you will be offered the opportunity to stop the interview. Contact details for support services and counselling services are provided below, should you become distressed either during or after your involvement with this project.

Contact details for support organisations

We understand that for some people being involved with research, such as this project, strong emotions can be triggered. Support is available during and after your involvement with this project by contacting SANDS. Call 1800 0 SANDS (1300 072 637). Alternatively, SIDS and Kids offer a range of support services, and can be contacted 24 hours a day via their bereavement support line. Call 1300 308 307.

Are there any benefits involved in participating?

We cannot guarantee any direct benefit to you as a result of participating in this study, however previous research indicates that some bereaved parents value the opportunity to share their story. The findings from this study may also provide wider benefits to the community. In particular, it is hoped that this study will contribute to health professionals' understanding of memory-making as part of end of life care in the neonatal unit. In this way, this study may help in improving the care that is provided to babies receiving end of life care and their families in neonatal units across the country.

How will my confidentiality be protected?

We intend to protect your anonymity and the confidentiality of your responses to the fullest possible extent, within the limits of the law. Your name and contact details will be kept in a separate, password-protected computer file from any data that you supply. This will only be able to be linked to your responses by the researchers. In the final report, you will be referred to by a pseudonym. We will remove any references to personal information that might allow someone to guess your identity, however, you should note that as the number of people we seek to interview is very small, it is possible that someone may still be able to identify you. The data will be kept securely in the Department of Social Work for five years from the date of final publication, before being destroyed.

How will I receive feedback?

Once the thesis arising from this research has been completed, a brief summary of the findings will be available to you on application at the Department of Social Work. It is also possible that the results will be presented at academic conferences.

Do I have to take part?

Participation in this study is completely voluntary. Should you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so without prejudice. Your decision to participate or not, or to withdraw, will not affect your relationship with this department or affect any services you may receive now or in the future.

Where can I get further information?

Please contact the researchers if you have any questions or if you would like more information about the project. The contact telephone number is: 0409 407 898. You may also email enquiries to r.thornton@student.unimelb.edu.au.

If you have any concerns about the conduct of the project which you do not wish to discuss with the research team please contact the Manager, Human Research Ethics, Office for Research Ethics and Integrity, The University of Melbourne, on ph: 8344 2073, or fax: 9347 6739.

How do I agree to participate?

If you are willing to participate, please call 0409 407 898 to speak with one of the researchers. Alternatively, you may email your contact details to r.thornton@student.unimelb.edu.au and we will contact you.

Appendix D: Social Media Post (example)



THE UNIVERSITY OF
MELBOURNE

“Memory-Making in Neonatal End-of-Life Care”

"This study aims to explore memory-making in end of life care for babies who die in the first weeks or months of life in a neonatal intensive care unit (NICU). Memory-making may include any activity that assisted you in forming enduring memories of your baby. Memory-making also includes the collection or creation of mementos designed to act as a reminder of your baby, such as personal items, clothing, photos or hand-prints.

Should you agree to participate in this study, you will be asked to participate in an interview about your perceptions of memory-making, as well as the effect that memory-making practices have had on your experience of loss. It is hoped that this research will help us identify those aspects of memory making which parents value, as well as identifying any practices which may be upsetting or otherwise harmful.

Participation in this study is completely voluntary and you would be free to withdraw at any time. We know that sometimes participating in research such as this can trigger strong emotions. Support will be available during and after your Interview.

If you would like more information or would like to participate in this project, please contact the primary researcher Rebecca Thornton by calling 0409 407 898. Alternatively, you can contact us via email (r.thornton@student.unimelb.edu.au) "

Appendix E: Interview Guide

Study: Memory-making in neonatal end-of-life care

Semi-Structured Interview Questions

As this study is being conducted according to the principles of Grounded Theory, the following prompts are designed as a starting point for a conversation between researcher and participant. Prompts will be altered or discarded if they do not fit the concerns of the participant or are for any other reason deemed inappropriate. Probing questions may also be added to encourage participants to expand on concepts they have raised.

Possible interview prompts include:

Can you tell me a little bit about (baby's name)?

Is there anything you did with (baby's name) in the hospital that you feel helped you remember him/her better?

How do you feel these activities affected your experience of loss?

Were there any activities you felt were particularly helpful? Any that were unhelpful or upsetting?

Did you bring any items home from the hospital to help you remember (baby's name)?

How do you feel these items have affected your experience of loss?

Are there any items you feel are particularly helpful? Any that are unhelpful or upsetting?

Is there anything you would like to see hospitals do to help parents who have experienced this type of loss to help them remember their baby?

Appendix F: Overview of the coding process for category "Contact"

Development of the sub-category "Contact" within the Key Category "Being a Parent"

Initial Codes (open coding)	Condensed/Removed (constant comparison between open codes)	Sub-Categories Developed (axial coding)
Having time with the baby	Condensed into:	Sub-category:
Visiting the baby	"Spending time with the baby"	"Spending time with the baby"
Having limited contact	Condensed into:	Sub-category:
Not having contact	"Limited contact"	"Restricted Contact"
Wanting contact		
Mother's medical condition		
Being separated	Condensed into:	
Baby being taken	"Being separated"	
Having access		Sub-category:
Being "allowed" contact		"Facilitated contact"
Being offered contact		
Being nearby		
Taking the baby outside		
Taking the baby home		
Unlimited contact		
Shifting focus: "cure" to "care"		
Touching the baby		Sub-category:
Holding the baby	Condensed into:	"Touching and holding the baby"
Having cuddles	"holding the baby"	

Memos about the developing category of “contact” taken from the NVivo Memo File for the study “Memory-Making in Neonatal End-of-life Care”

Theoretical Memo: 17th March 2016

Contact is required for parents to engage in parenting activities. Seeing, holding, touching, and care-giving all required sustained and supported contact with the baby. Contact is a condition for all other aspects of the major category of parenthood. (*methodological note: “parenthood” was re-labelled “being a parent” during the course of an analysis to draw on participants’ own words and to denote the active nature of the relationship – participants needed to engage in parenting activities to become parents – this was not an automatically acquired status*).

Theoretical Memo: 19th June 2017

The category of contact has multiple dimensions and occurs along a continuum - from separation (where there was no contact) to restricted contact, where parents are discouraged from visiting or otherwise have access to their baby hindered, through to facilitated contact, where parents are given free access to their baby, ideally in a private space, with no time restrictions. Properties of contact include being with the baby/spending time together as a family and physical contact (touching and holding).

Theoretical Memo: 12th December 2017

Having time with the baby was an important memory making activity in itself - at this point I also believe that having time with the baby as a family supports the development of a social identity for the baby - being able to be together "as a family" helped the baby become "part" of the family. Need to ask the next few participants specifically about this if contact emerges as important in the next few interviews.



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Author/s:

Thornton, Rebecca Kate

Title:

Memory-making in neonatal end-of-life care

Date:

2019

Persistent Link:

<http://hdl.handle.net/11343/224196>

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